

**Putting Phenomenology into
Practice - Towards an Ontology of
Person Centered Healthcare**

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Abstract

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In this research I have set out a philosophical basis for person centered healthcare. I have uncovered the philosophical ground on which this rests in an attempt to show how practice can be improved, and how examples of person centered practice can be transferred between individuals and institutions involved in the commissioning and provision of healthcare. Philosophy is the instrument through which we understand why systems work and philosophy is therefore the key to unlock the potential of person centered healthcare. By providing an underlying architectonic this work will help to enable practitioners to understand the benefits of person centered healthcare practice in promoting autonomy in those who are suffering from chronic and other illnesses.

I have used the existential phenomenology of Martin Heidegger and Gadamer's work on hermeneutics to provide support to the argument in favour of a person centered approach to healthcare. Phenomenology offers a rich and subtle way of thinking about how we know what we know, and this applies to our knowledge and understanding of how healthcare works just as much as it does to all other kinds of knowledge. Existential phenomenology, with its emphasis on the first person lived experience of people who are ill and receiving care provides a method of discussing, understanding and grounding person centered healthcare which is philosophically robust, and which offers policy makers, and those commissioning and providing healthcare, clear guidance on how to make their practice person centered.

Using examples from my own experience of illness and healthcare along with account given by others I have shown how the purpose of healthcare is understood as the preservation, restoration and maximisation of personal autonomy, how a person centered approach is the most appropriate response to this purpose, and how the philosophical ground

which I have set out becomes manifest in the practice of person centered healthcare.

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Chapter One - Introduction

You put the interests of people using or needing nursing or midwifery services first. You make their care and safety your main concern and make sure that their dignity is preserved and their needs are recognized, assessed and responded to. You make sure that those receiving care are treated with respect, that their rights are upheld and that any discriminatory attitudes and behaviours towards those receiving care are challenged.¹

You must be polite and considerate.

You must treat patients as individuals and respect their dignity and privacy.

You must treat patients fairly and with respect whatever their life choices and beliefs.

You must work in partnership with patients, sharing with them the information they will need to make decisions about their care.

You must support patients in caring for themselves to empower them to improve and maintain their health.²

These are fine intentions from two United Kingdom professional bodies, the Nursing and Midwifery Council and the General Medical Council, from which we draw most of the people who look after us when we are unwell. It is interesting to reflect, even at this early stage of the discussion that, in the two codes of good practice, we seem to have what appears to be already a person, or at least patient, centered approach. We might in the circumstances be tempted to ask them to just “get on with it”. However, in neither of these admirable expressions of intent do we see any philosophical ground for the approach they recommend and without this we cannot be sure that the aims they intend will be delivered. It is also interesting to see that the code of good practice for nurses talks about “people” while the equivalent code for doctors refers to “patients”. This difference is repeated throughout the full text of these codes of practice and may well reflect underlying philosophical differences. These philosophical differences may begin to tell us, as we proceed with the argument, something about what it is to be a patient and what it is to be a person, and why this might be important when we consider how we are treated.

While the meaning in the codes of practice at first appears clear it becomes problematic the moment we begin to try to define. It feels as if we all think we know what we mean when it comes to person centered healthcare, but as soon as we discuss the subject our differences become more apparent than the commonality that we thought we all shared. Few, if anyone, would disagree with these fine intentions but the question as to what they really mean remains at best contentious and at worst unclear. We do not really understand what success looks like in respect of these intentions or how to devise systems which will guarantee their delivery in practice. This is a problem; and in order for these intentions to be put into widespread everyday practice we need to gain a deeper understanding of their intellectual origins and thereby to understand what we really mean.

The policy context for person centred care in the United Kingdom is evident to anyone looking at the output of NHS England³ and other associated organisations, where a wide range of person centred care initiatives are being promulgated ranging from individual budgets for some patients with long term conditions to proposals to engage service users in the planning and design of services. This has also included the development of NHS sponsored organisations to promote person centred care like the Coalition for Collaborative Care which now sit alongside more independent organisations like the Health Foundation which is producing work intended to promote person centred care⁴ and the Point of Care Foundation.⁵ The output of all of these organisations, together with the work of professional bodies like the General Medical Council and the Nursing and Midwifery Council, sets the context for the development of person centred care in the United Kingdom.

This is not the place to examine in detail the many initiatives that are being brought forward. For the purposes of this work it is sufficient to say that in the United Kingdom Health Service the idea of person centred care is receiving large amounts of attention and work but without the benefit of a robust philosophical understanding of the notion itself, which is what I propose to offer in this work. As a philosopher it is not for me to evaluate

or criticise any of the current initiatives which are intended to promote or to use a person centered approach, as a philosopher my primary intent is to use the insights offered by philosophy to understand the intellectual territory and to offer clear thinking about the topics under discussion, with the intention that this clarity should provide those who make policy a firm basis on which to base their own work. This is the aim of this work.

Why Philosophy?

Philosophy is the instrument through which we understand why systems work because philosophy is argumentative, the more argumentative the better,

It proceeds by way of arguments, and the arguments are argued over. Everything is aired in the bracing dialectic wind stirred by many clashing viewpoints. Only in this way can intuitions that have their source in societal or personal idiosyncrasies be exposed and questioned.⁶

The purpose of philosophy is to unsettle us and to make us question ourselves, to make us unsure about what we think and do, and to constantly challenge ourselves in order to be the best we can. Neither can the power of philosophy be denied as Gadamer points out,

for philosophy ... I take care to tell my students: you must sharpen your ear, you must realize that when you take a word in your mouth, you have not taken up some arbitrary tool which can be thrown in a corner if it doesn't do the job, but you are committed to a line of thought that comes from afar and reaches on beyond you.⁷

As the powerful process which concerns itself with looking into the presuppositions of arguments, and in creating consistent foundations for new positions and arguments, philosophy becomes the key to unlock the potential of person centered healthcare. This work will begin to uncover the philosophical basis of person centered care by a process of presenting and critically evaluating arguments which support a person centered approach to healthcare. This will then show both how practice can be improved and how examples of good practice in this area can be transferred between the individuals and institutions involved in the commissioning and provision of

healthcare. By establishing a robust philosophical basis for a person centered approach to healthcare those involved in the provision and commissioning of care will be provided with an intellectually consistent method with which they can achieve their aim of giving help to those who need it, and in the ways that they would like to have it given.

Why person centered healthcare?

The promotion of a person centered approach to the commissioning and provision of healthcare is stimulated from two quite different directions. The first is a deep rooted feeling that it is inappropriate to treat humans like ourselves as anything other than just that (whatever “that” might be). The second approach is more simply practical as a response to the increasing numbers of people in Western societies who are living with long lasting chronic illnesses, and who require care (sometimes only a little care, sometimes a lot) to live their lives. This creates a problem in that large numbers of people now require often expensive care to be provided by services, which in their turn consume more and more of the wealth of these societies. The question as to how these services are to be paid for becomes increasingly pressing. In a way this is a problem that is of our own creation. Not so long ago many of the conditions with which people now live well would have killed them quite quickly, diabetes and left side ventricular failure to name but two. Advances in medical technology have resulted in many of us living longer lives but without the benefit of perfect health (whatever that might be) and the question as to how to provide us with the care we need in the most cost efficient way becomes paramount and, so the argument goes, drives us in a person centered direction.^{8,9} Supporters of a person centered approach to the commissioning and provision of this kind of care suggest that this approach offers a way of coping with large numbers of people who need care. By treating people as individuals and by tailoring the care they get to their individual needs they are helped to become more self-reliant and therefore less dependent on health and social care services. The shorthand for this case is “making patients into persons”, or to put it another way to avoid making persons into patients. Increased self-management by independent people who are

living with illness reduces the pressure on health and social care services and makes these systems tenable. This second approach makes an appeal to the presumption that people who receive person centered care are made more confident, more independent and therefore less dependent on services. The theory that some kind of “health activation” produces long term benefits has begun to show that, by engaging with the everyday lives people who are unwell, systems and practitioners can improve outcomes and perhaps reduce costs.^{10,11,12} While this work makes a practical case for a person centered approach to healthcare it still rests on an unexamined presupposition about what constitutes person centered healthcare in the sense of an underlying relationship between those who provide care and those who receive it.

The thing that both of these approaches have in common is that neither rests on any clarity of meaning as to what we understand as person centered care. The third approach and the one which I propose to develop in this work is that Being-with-Others is *constitutive* of the Being of each and every one of us. Not only do we live in a world with Others like ourselves but the being of these Others is so closely tied up with our own being that the relationship is mutually constitutive. In terms of healthcare this will lead us to the notion of authentic solicitude as the ground for the provision of care to Others when they are unwell. This approach, by showing the nature of the relationship of our own being to the being of Others, provides us with a strong reason why we should behave in the explicitly other regarding way that is manifested in person centered healthcare. It is the task of philosophy not to direct the decisions we make about the creation of values (to tell us what we ought to do) but to inform the choices we make. It is true that, even with this knowledge, we may choose to act in such ways that will jeopardise the necessary structures of our own Being, but it makes such choices less appealing and therefore less likely, and in this way, provides a more robust ground on which the advocates of person centered healthcare can make their arguments.

Phenomenology

The philosophical method that I will primarily employ will be phenomenology, and specifically the existential ontological phenomenology of Martin Heidegger. Phenomenology offers a rich and subtle way of thinking about how we know what we know, and this applies to our knowledge and understanding of how healthcare works just as much as it does to all other kinds of knowledge. Phenomenology, with its emphasis on the first person lived experience of people who are ill and receiving care provides a method of discussing, understanding and grounding person centered healthcare which is philosophically robust, and which offers policy makers and those commissioning and providing healthcare clear guidance about how to make their practice, and their services, person centered. In effect phenomenology will give us an epistemology and an ontology of person centered healthcare. However, it is in the nature of phenomenology (and particularly the phenomenology of Heidegger) that it provides us with demonstrations rather than the kind of proofs that we might conventionally look for. The emphasis which this method places on first hand lived experience and the first-hand accounts of individuals means that to understand what is being said we need somehow to experience these demonstrations ourselves. In Heideggerian fashion the truth is to be revealed or unhidden¹³ and it will be directly related to the context we find ourselves in. When it comes to phenomenology we either “get it” or we don’t. This means that it takes a specific kind of (phenomenological) reflection, as found in the works not only of Heidegger and Gadamer but in writers like Sebald¹⁴, to appreciate what we can gain in understanding from our experience of the world, and the strength of the case can only be judged according to how successful it has been in helping us to gain this understanding.¹⁵ In view of this, in some of its aspects, this work will not only use the insights of phenomenology, but it will be phenomenological itself. To achieve this I will use examples of real life experience of healthcare to illuminate the philosophical architecture. By using anecdotes and personal examples I will show how phenomenology can illuminate our thinking about healthcare, all the way from the level of an encounter between an individual patient and a clinician

to the level of healthcare commissioning and large scale provision. This means that this work will be a combination of philosophical argument, first hand personal reflection (my own), and second hand personal reflection (the published reflections of others who have written about their own illness and the illness of others). We begin and end with our experience of care; this will result in an approach which recognises clear roles for everyone involved, including those who receive care, and puts their experience at the heart of everything we do. I will set out how people who are ill, individual practitioners, commissioners, and institutional providers can use a phenomenological approach to improve services, charting a route from philosophical theory into healthcare practice. Any piece of philosophy which does not set out to have an effect on the way that we behave is of very limited worth, and philosophy in the area of healthcare which makes no attempt to improve the experience of healthcare seems to me to be a pointless exercise.

This approach is of particular interest to me not only as a philosopher with a special interest in Heideggerian phenomenology, but as someone who has experienced serious chronic illness while working as a senior manager in the United Kingdom National Health Service. My own reflections, on my own experience of being responsible for the delivery and development of services, combined with my later experience of being on the receiving end of services has supported the development of the ideas expressed in this thesis. To summarise, after working as a manager specialising in primary care for eighteen years I was forced to retire due to ill health (ulcerative colitis) in 2004, and in 2009 underwent surgery for the construction of an ileostomy. In a move similar to that described by Havi Carel in her work *Illness*¹⁶ I was able to use the insights given to me by the study of philosophy to understand what was happening to me and to recognise the value of my experience in gaining an understanding of the nature of illness and being unwell. My background in healthcare, philosophy and as a patient has been valuable in the construction of this thesis.

Summary

The work will proceed as follows. In the next section (Chapter Two) I will aim to provide a sound philosophical basis for the argument which will include a setting out of the nature of our relationship with those we call Others. For this we will need an outline of Heidegger's phenomenological ontology and to show how he arrives at the equation;

$$\text{phenomenology} = \text{hermeneutics} = \text{ontology}$$

This equation will provide the philosophical basis for the entire argument and will be combined with the hermeneutics of Hans Georg Gadamer¹⁷ to develop what I will call a hermeneutic of healthcare in which the healthcare system will be understood as the sum of all of the encounters between those who seek help with their health problems and those who offer this help. This means that the healthcare system has no fixed identity and is constantly in flux and changing. It also means that it is not describable by any conventional means. If we accept this understanding then we take a hermeneutic approach to our study of the philosophy of healthcare. Under this approach the details of the system (individual encounters) can only be understood in the context of the whole system and conversely the whole system can only be understood in relation to the details (individual encounters). We are therefore returned constantly to the individual encounter. In this chapter, by clarifying what we mean by the healthcare system and by gaining an understanding of what it is to be in a world with Others, I will prepare the ground on which a person centered approach to healthcare can be built in a way which is consistent with our fundamental ways of existing in the world.

In Chapter Three I will argue that autonomy is the end of healthcare. Illness is experienced as the inability to do things that we have been used to doing; a gap opens up between our willed existence and our biological existence. We can no longer do the things that we want to do. In illness this is experienced as a sudden or relatively sudden loss of ability to act as we will, while in ageing the loss is more gradual and therefore less noticeable. In both cases the loss is, at bottom, a loss of personal autonomy. In the

case of illness, when this loss becomes more than we can manage, we consult someone with expertise in healthcare as a means of seeking the assistance we need to restore our previously experienced autonomy. Of course the notion of autonomy is not always simple, and I will discuss some of these complexities in this chapter, but It remains clear that while there are many varied and complex scenarios that occur every day in every healthcare system all of them, however complex and varied, conform in essence, to this basic analysis of loss and attempted restoration of autonomy.

In Chapter Four I will consider in some detail the relationship between what it is to be a patient and what it is to be a person and why this matters. I will do this using a discussion of Heidegger's notion of solicitude as our way of being-with-Others. This will also include a consideration of the dialectical relationship between clinicians and their patients and the idea of mutually informed consent. This in turn will lead to the setting out of the barriers to person centered healthcare and some of the ways that these may be overcome through the process of normalising care, as part of the process of restoring and maximising autonomy.

In Chapter Five I will use the very personal reflections of Havi Carel^{18,19} and Atul Gawande²⁰ in a discussion of living well with illness and of dying well, and the ways that person centered care can make this easier. I have chosen these two authors because their work on illness is more than simply descriptive and anecdotal. Both provide the necessary philosophical reflections that are required to advance towards the development of a robust philosophical basis for person centered healthcare which is the aim of this thesis. In particular the combination of accounts of her personal experience and the philosophical grounding of this experience make Carel's work both compelling and philosophically potent, and her use of Heideggerian existential phenomenological ontology allows her to extend her understanding of her own illness to a wider interpretation of what it is to be unwell. In the case of Gawande although the philosophical ground is not made quite so explicit his reflections on the cases he presents point

towards the same philosophical mechanisms that are used by Carel. I am aware that there are many other accounts of the experience of illness but within the confines of this thesis and its limited aims I am satisfied that these two, along with references to some of my own periods of serious illness are sufficient for the case to be made.

In addition to using the work of Carel and Gawande in this chapter I will show how the ontology which I believe underpins person centered healthcare is revealed in the practice of end of life or palliative care.²¹ This will, not surprisingly, turn out to be a species of what is now termed holistic care, an expression more commonly heard in nursing circles than in those inhabited by doctors, but which has really been around for much longer than the terms we now use to give an account of this kind of care. It includes consideration and sympathy for others, respect for individuality, attending to the psychological and “spiritual” needs of patients and simply caring. Philosophically understood, these ways of caring, represent authentic being in the practice of healthcare. While this way of caring is perhaps most prominent in palliative care, I hope to show that it can be central to person centered care in the delivery of healthcare in all sectors.

Chapter Six will conclude the work and show in summary why a person centered approach to the commissioning and provision of healthcare works, not only for those of us who need care but for those who organize and pay for it. The central importance of personal autonomy and self-management will now be apparent as the most significant features of any system of person centered healthcare. I will refer briefly to two examples from my own experience; the first of coping with serious illness and the second of implementing a large clinical effectiveness programme in United Kingdom General Practice.²² My endeavour in this section will be show how the philosophical structures which I have shown to underlie person centered healthcare can be effective in the practice of commissioning and providing healthcare, and furthermore, how the lessons that we can learn from these examples, and from the philosophical approach that I have been using, can be applied in many other areas of healthcare.

Chapter Two - Phenomenology, Ontology, Hermeneutics

If the question at issue is, “Why person centered care and not some other approach?”, then the answer I will first propose is that person centered care is a manifestation of fundamental ontology; that is, it is a function of what it means to be authentically human. To achieve this I will use Heidegger’s phenomenological ontology and Gadamer’s hermeneutic approach. The combination of existential phenomenological ontology and hermeneutics will provide a powerful basis for all of the succeeding arguments by re-framing the case for person centered healthcare in terms of the first hand lived experience of those giving and receiving care, and by using an understanding of the healthcare system as a dynamic totality. This chapter will give an explanation of my use of the terms, phenomenology, ontology and hermeneutics and their relation to an understanding of healthcare. Once this is done I hope that I will have made the philosophical case for person centered healthcare clear and compelling. The nature of the methodology that I am using is such that I will be able to issue no categorical imperative in favour of person centered care. In fact this methodology challenges the very nature of such imperatives as we might expect to understand them. In what will be a fundamentally existential approach to an understanding of illness, and by implication healthcare, we will have no more than a demonstration of what constitutes effective healthcare rather than any kind of proof of the superior nature of person centered healthcare. Working with a Heideggerian notion of truth, as that which is revealed rather than truth as concerning the correctness of propositions,²³ our interpretation will uncover the truth of illness and healthcare. Both Heidegger and Gadamer (and the others who use their work) do not seek to “prove”, their aim is an interpretation of everyday experience leading to understanding. In the context of healthcare this means an interpretation of the experience of illness and of receiving care, leading to an understanding of the meaning of healthcare, (“meaning” in this sense being equivalent to that which makes it possible). Although at times the argument may appear at best inconclusive this is simply in the nature of this kind of reasoning in that it is fundamentally based on and

concerned with our first hand lived experience of the world. This experience is not accessible to external validation by another consciousness, so it will still remain for us all to decide whether or not we accept these interpretations.²⁴ In the end I believe that philosophy can only move us forward in the direction of understanding, and that is what I intend to do here.

Phenomenology

Bachelard puts it lyrically when he describes phenomenology in *The Poetics of Space* as, “consideration of the *onset of the image* in an individual consciousness.”²⁵, thereby calling to our notice the central importance of personal experience. Heidegger is more forthright when he says,

We shall maintain that phenomenology is not just one philosophical science among others, nor is it the science preparatory to the rest of them; rather *the expression “phenomenology”* is the name for the *method of scientific philosophy in general*.²⁶

Heidegger thus places phenomenology at the centre of any and all philosophical investigation, including our investigation into person centered healthcare. Heidegger’s affirmation will resound throughout all of the succeeding arguments in this work.

Phenomenology is the study of things as they appear to us as distinguished from what they “really” are, whatever that might be. We cannot experience things which are beyond our experience, that much is obvious, so the way that we experience the world, and the things we discover in appearance, becomes central to our understanding (some would say knowledge) of the world. This, as we shall see in good time, includes our understanding of illness. Phenomenology prioritizes the first hand lived experience of individuals, these singular subjective accounts are complementary to any other accounts that we might create, and taken together all of these accounts give us a complete picture of what we call world so that,

Phenomenology might be introduced as the attempt to found a conceptual apparatus based on lived experience—the first-person

perspective—in contrast to the theories and investigations of empirical science—the third-person perspective.²⁷

Heidegger's phenomenology gives prominence to the everyday and to the interpretation of Dasein in what he calls, "average *everydayness*".²⁸ Dasein is Heidegger's term for the being that we all have to be. The literal translation would be "being-there" but this does not reflect the depth or breadth of this central notion to Heidegger's thinking. Above all Dasein does not denote the isolated experiencing subject. Dasein is more of an activity or a process, indeed we find Heidegger's work all the more accessible when we look on what might be nouns (being) as verbs (being). In this way the dynamic form of Heidegger's analysis is preserved. For Heidegger phenomenal entities (entities that can appear) have their being both spatially and temporally and to forget or omit consideration of either one of these leads to misunderstanding. The notion of Dasein encompasses both of these aspects of our being.²⁹ Everydayness is precisely what it appears to be, the ordinary everyday existence that we all have every day, so that,

"Everydayness" means the "how" in accordance with which Dasein "lives unto the day", whether in all its ways of behaving or only in certain ones which have been prescribed by Being-with-one-another. To this "how" there belongs further the comfortableness of the accustomed.³⁰

And,

Everydayness is a way *to be* - to which, of course, that which is publicly manifest belongs. But it is more or less familiar to any "individual" Dasein as way of existing which it may have as its own.³¹

This means that his analysis of both Dasein and world is rooted in our everyday experience of the world; we begin with and return to the everyday. Heidegger's interpretations gain their strength from the ways that, through the priority given to the everyday, they arrive at understandings of the world which are in tune with, rather than at odds with, these everyday understandings. These are the ways of being in the world that we use all of the time, and yet we do not require any necessary appreciation or understanding of why we do what we do in our everyday lives. We are phenomenological beings even when we do not realise it.

Why not Phenomenology?

Jonathan Sholl has attempted to show the limitations of the use of phenomenology in this area, in particular how it is used by Svenaeus, Carel and Toombs.³² All of these three use the work of Heidegger and Gadamer and I believe that Sholl's criticism is based on an important and fatal misreading of the truly radical nature of Heidegger's position. However, it is important to address briefly the approach that Sholl takes before proceeding any further with the argument. This will also begin to demonstrate just how different is Heidegger's, and my own, approach to the question. Sholl says,

By beginning from the idea that humans are intimately connected to their world through their body, it seems clear that understanding illness requires an understanding of how this bodily connection is disrupted and how this, in turn, alters other aspects of human experience, such as spatiality and temporality.³³

But this is a mistaken beginning; we are not intimately connected with the world but, as Heidegger would say, *worldly*. The difference is crucial in that Heidegger will not brook any kind of separation between consciousness and world so the question of the intimacy of our connection can never arise. To introduce this question betrays a residual alliance to the notion of an isolated subject consciousness and means that Sholl's argument will inevitably miss the point. Heidegger is clear that if we choose this kind of starting point we can never understand the nature of being. We will be continually misled in our understanding of being back into the corral of the isolated Cartesian subject in which we are each understood as individual but separated thinking beings. Under the Cartesian analysis the relation we have to other beings like ourselves and even the inanimate entities that make up our world becomes automatically problematic, this is a problem that Heidegger will not set. Sholl continues with,

First, it is often claimed that since we are necessarily embodied beings, it is problematic to think that the self 'has' a body. Rather, for a phenomenologist, we do not have our bodies, but we are our bodies. The claim, then, is not that the self can be reduced to the body, but that the body is fundamentally a lived body: 'my body is me'. Moreover, as this embodiment entails that our consciousness

is also embodied, we cannot separate, either conceptually or empirically, consciousness and body; body and mind are unified or integrated in our lived experience of the world.³⁴

This again is a fundamental misconception of Being-in-the-world and one which persists throughout Sholl's paper. The Cartesian paradigm does more than separate body and mind; it treats them as distinct objects to be categorized so that the separation of these two "things" found in Descartes is itself a product of the misunderstanding of being-in-the-world. Heidegger's phenomenological ontology first and foremost rejects any approach of this kind.³⁵ Be-ing is a verb and a process not a noun and a thing. Sholl continues to betray a residual alliance to the notion of an isolated subject which is specifically rejected by Heidegger and those like Svenaeus, Carel and Toombs who use Heidegger's existential phenomenological approach in their understandings of illness and the process of healthcare. Sholl fails to appreciate that what Carel, Toombs and Svenaeus provide is a hermeneutic interpretation of illness and which therefore encompasses all aspects including both the natural and the phenomenological.

Sholl argues that naturalism, an approach which broadly suggests that illness can be defined in terms of physical symptoms and observable variations in the body, when it is expanded to take into account the subjective appearance of illness in addition to objective measurement, makes the recourse to phenomenology unnecessary. However, this fails to appreciate that, while it may be the case that naturalism can accommodate the idea of first person experience into our understanding of illness, the broader point is that naturalism itself rests on the phenomenological basis and is a product of phenomenology. In this case it is no surprise that naturalism can accommodate first person experience. It is not the phenomenologist who must fit in with the scientist but the other way around. Sholl is accepting and criticizing the existential nature of the interpretations provided by phenomenologist, but he is failing to see the connection between this approach and the underlying hermeneutics of phenomenological ontology. Rather than requiring an expansion to include

the natural, phenomenology already includes naturalism. In effect Scholl's position rests on phenomenological presumptions. It is at times like this that we need to remember Heidegger's position with regard to phenomenology.

We shall maintain that phenomenology is not just one philosophical science among others, nor is it the science preparatory to the rest of them; rather *the expression "phenomenology"* is the name for the *method of scientific philosophy in general*.³⁶

In effect Sholl underestimates the radical nature of Heidegger's work in completely reframing the question of our relation to Others and to the world and therefore changing the starting position for the discussion. We cannot begin with the isolated subject consciousness, and if we make the attempt then we will fail to gain any understanding of the relationship between consciousness and world which is at the root of the phenomenological understanding of illness. We are most usefully guided here by Heidegger when he says,

We said that we wanted to *feel our way forward* to the essence of truth as unhiddenness. This meant: we are dispensing with a *definition*. Perhaps a definition is precisely what is least suitable for grasping an essence. It is not a matter of capturing this essence in *sentences* (or in a *single* sentence) that we can repeat and pass on. The sentence as such says least of all. Instead it is a matter of feeling our way, of asking if, and how, unhiddenness *consists in*, and has its origins in, the unity of the indicated connections.³⁷

The question must be "What is the meaning of Being (illness), as in what makes it possible?" rather than the sterile "What is it?"³⁸

Phenomenology and Illness

While Heidegger's understanding of phenomenology gives this approach a pre-eminent position in any enquiry about human experience and understanding, it is the way that phenomenology gives priority to the accounts that we are able to give about our illness which give the method its power when we consider person centered healthcare. These everyday accounts are the stock-in-trade of Heideggerian phenomenology and as such become central to any discussion of person centered healthcare. Just as we begin with the everyday Being of Dasein in our inquiry into the nature

of the Being of Dasein, so we must begin our inquiry into the nature of illness and healthcare with the everyday experience of those who are ill. Indeed where else is there to begin? Glendinning, quoting Frege, makes the point vividly with, “Someone can have sympathy for me but still my pain always belongs to me and his sympathy to him”.³⁹ Havi Carel makes the case much more fully in her work *Illness* when she distinguishes two common approaches to the understanding of illness; the naturalistic (mechanical) and normative (comparative) conceptions of illness⁴⁰ and explains how both of these, even when taken together, are inadequate to provide us with a complete notion of illness. To achieve this we must add an account of what it is like to be ill. Once we have this we can begin a phenomenological interpretation of illness and eventually bring out an understanding of what it means to be ill. This will in turn point towards a person centered approach to healthcare as the most appropriate response to those who are unwell. In Heidegger’s terms if we are to understand the nature of illness and to come to some conclusions as to how to treat it we would best attempt a phenomenological interpretation of the Dasein who is unwell. I will return to this in more detail later,⁴¹ suffice to say, for the moment, that phenomenology will be the guiding methodology in this work.

Heidegger and the Question of Other minds

The problem of “others” and “other minds” has entertained generations of philosophers and attempts at a solution are many and varied, both in form and success. The only thing that is certain is that unless we can find a way of thinking which avoids placing a difficult (some would say unbridgeable) gap between those who provide care and those who receive it then we will find it hard to justify a person centered approach to healthcare. On the other hand, if this ground can be gained, and this perceived gap between us can be eliminated, we will be able to begin to show how and why person centered care is the appropriate approach to take in the provision of healthcare.

Heidegger brings a new approach to the question when (paraphrasing Kant)⁴² he says of the problem of other minds, “The ‘scandal of philosophy’

is not that this proof has yet to be given, but that *such proofs are expected and attempted again and again.*"⁴³ Heidegger immediately recognises that the source of the problem is the notion of the isolated subject, when he says,

In clarifying Being-in-the-world we have shown that a bare subject without a world never 'is' proximally, nor is it ever given. And so in the end an isolated "I" without Others is just as far from being proximally given.⁴⁴

The answer to the question "what is it?" when applied to ourselves or to Others must always result in a reply in terms of a kind of "thing" (in Descartes case a thinking thing)⁴⁵ and, Heidegger claims, this attempt at categorical definition means that the answer will always be inadequate in terms of the existential entity under investigation. We are above all an entity which has both possibilities and connections as constitutive of our Being.

In making this beginning Heidegger resolves to bring an existential and phenomenological analysis to bear on the question of the being of Dasein and of Others, as opposed to the unremittingly categorical interpretation demanded by Descartes and his successors. Heidegger does not offer a solution to the problem of other minds in the traditional manner, he re-frames the question in such a way that the problem disappears as a problem.⁴⁶ He discusses and dispenses with accounts which rest on the notion of the isolated subject and demonstrates that we exist as both Being-in-the-world and as Being-with-Others, so that, "Others are encountered *environmentally*" (and) "the world is always the one that I share with Others. The world of Dasein is a *with-world* [*Mitwelt*]." ⁴⁷ This goes much further than a simple affirmation that we exist in a world alongside Others. Dasein is *only* to be understood as active within the world of things and Others. No radical separation between Dasein and world, and therefore between Dasein and Others can be made. Within the world we encounter Others and,

These entities are neither present-at-hand nor ready-to-hand; on the contrary, they are *like* the very Dasein which frees them, in that *they are there too and there with it.* ⁴⁸

Of course, remembering that, “‘With’ and ‘too’ are to be understood *existentially*, not categorically.”⁴⁹ When we come to understand the world and to use equipment we find that Others, like ourselves, have already given their own meaning to the world and to entities that we engage with. As he says in a rather picturesque manner,

When, for example we, we walk along the edge of a field but ‘outside it’, the field shows itself as belonging to such-and-such a person, and decently kept up by him; the book we have used was bought at So-an-so’s shop and given by such-and-such a person and so forth. The boat anchored at the shore is assigned in the Being-in-itself to an acquaintance who undertakes voyages with it; but even if it is a ‘boat which is strange to us’, it is still indicative of Others.⁵⁰

It is through unremitting existential analysis that we gain an authentic understanding of our own Being and of the Being of Others not as separate “things” but as beings *constitutively* engaged and involved. We are what, and who, we are because of Others. In this way Heidegger cements both the unity of Dasein and world, and the unity of Dasein and Others. This has been achieved not by bridging the gap, assumed by Cartesians and post-Cartesians, between ourselves and Others, but by showing that there is no gap in the first place. Our understanding of the relation between ourselves and Others as isolated entities cannot account for our everyday experience of the world, it is thus shown to be deficient in providing an understanding of everyday Dasein. It is now unity which is to be fundamental to being and not separation. If it is the case that we are constitutively related to Others, and that this relation is both fundamental and inescapable then we may only choose how we conduct this relationship. How we behave towards Others has become a matter of ontology. As Frank says with reference to the work of Levinas,⁵¹

Living *for* the other is not... an act of exemplary goodness. Persons live *for* others because their own lives as human beings require living that way. The self is understood as coming to be human in relation to others and the self can only continue to be human by living *for* the Other.⁵²

This has clear implications for the case in favour of a person centered approach to healthcare, but I will leave making these more explicit to a later chapter of this work when I set out and discuss Heidegger's notion of solicitude,⁵³ before that it is necessary to address the overall question, What do we understand by the Healthcare System?

Hermeneutics

For the purposes of this discussion I will understand the healthcare system as the sum of all of the encounters between those who seek help with their health problems and those who offer this help, I think that this approach provides an account of the healthcare system which will be familiar to those who work in the system and to those who receive care, as well as offering a philosophically robust and rich account of healthcare systems and the ways in which they operate. I will first elucidate this method using the work of Hans Georg Gadamer⁵⁴ and then endeavour to see what consequences arise for our understanding of the healthcare system and the case for person centered healthcare.

When he considers the nature of experience Gadamer says, "That life manifests itself in experience means simply that life is the ultimate foundation"⁵⁵, and then, "The unity of experience as determined by its intentional content stands in an immediate relationship to the whole of, to the totality of life."⁵⁶ This is obviously reminiscent of Heidegger's emphasis on the everyday in his analysis of Dasein. We begin with our own experience of our own lives, but these experiences are not any kind of disconnected phenomena randomly following one another. Together they make up the very fabric of our lives, so that,

Every experience is taken out of the continuity of life and at the same time related to the whole of one's life. It is not simply that an experience remains vital only as long as it has not been fully integrated into the context of one's life consciousness, but the very way it is "preserved and dissolved" (aufgehoben) by being worked into the whole life consciousness goes far beyond any "significance" it might be thought to have. Because it is itself within the whole of life, the whole of life is present in it too.⁵⁷

When this is combined with, “The significance of that whose being consists in expressing an experience cannot be grasped except through experience.”⁵⁸ We can see that Gadamer’s method (like that of Heidegger) is both existential and phenomenological. His explicit assertion of the centrality and individuality of human experience comes together with the recognition that the significance of this experience is to be found not in the experience itself but in the context of the “*totality of life*”. This gives us a phenomenological hermeneutic, an understanding of experience from within experience itself. In Gadamer’s world there is no “outside” no possibility of separation between ourselves and the world we experience, and consequently no separation between ourselves and the “Others” we encounter in experience. Like Heidegger before him Gadamer presents a direct challenge to the categorical ways in which we have been used to understanding both ourselves and our experience of the world. We can now see how Gadamer derives what he calls “the hermeneutical rule”

Let us next consider how hermeneutics goes about its work... We recall the hermeneutical rule that we must understand the whole in terms of the detail and the detail in terms of the whole. This principle stems from ancient rhetoric, and modern hermeneutics has transferred it to the art of understanding. It is a circular relationship in both cases. The anticipation of meaning in which the whole is envisaged becomes actual understanding when the parts are that are determined by the whole themselves also determine this whole.⁵⁹

This means that,

The harmony of the all the details with the whole is the criterion of correct understanding. The failure to achieve this harmony means that understanding has failed.⁶⁰

Understanding is achieved when we experience harmony between the detail and the whole. The attempt to make a categorical definition of anything is misguided because this beginning, in which we remove the entity under investigation from the context in which it is set, will precisely defeat our attempt to understand. In the same way that Heidegger sets each individual Dasein in the context of a world in which we find entities like ourselves (Others) so Gadamer recognises the contextuality of all experience. We all have our own unique experience of the world and it is

the harmony between the unique accounts of our experience and equally unique accounts given by Others which gives us what we call world. The same can be said of healthcare systems in which we seek the harmony of the parts and the whole, such harmony is offered by a person centered approach because it remembers and reinforces the importance of the individual encounters which make up the system as a whole. Again we are reminded of Heidegger's advice with regard to the nature of truth.⁶¹

If we apply this hermeneutic approach to the healthcare system it means that the system has no fixed or categorical identity and is constantly in flux and changing. It also means that it is not describable by any conventional means. If we understand the healthcare system to be the sum of all of the encounters between those who seek help with their health problems and those who offer this help, then we take a hermeneutic approach to our study of healthcare systems. The objects of our investigation become the individual accounts of the workings of the system given by all of those involved in the system, each one derived from their own unique experience of the system. Under this approach the details of the system (individual encounters) can only be understood in the context of the whole system and conversely the whole system can only be understood in relation to the details (individual encounters), so that in seeking understanding of the system we seek the harmony between these parts and the whole. Just as we gain the "*totality of life*" through a hermeneutic approach to all experience so a hermeneutic approach to healthcare systems will give us the totality of healthcare. As Gadamer says of world history,

The context of world history—in which appears the true meaning of all the individual objects, large or small, of historical research—is itself a whole, in terms of which the meaning of every particular is to be fully understood, and which in turn can be fully understood only in terms of those particulars.⁶²

Just as hermeneutics is the foundation for the study of history so will it be the foundation for our study of healthcare systems and practices. What is more the kind of understanding we gain will be not quite like the one we might expect because, "Hermeneutics is an *art* not a mechanical process.

Thus it brings its work, understanding, to completion like a work of art⁶³. Once again, we are not looking for, and will not find, a definition of the healthcare system and we will be unable to recognise what we find in these categorical terms. The system resists this kind of definition because it is not a “thing” at all but an ongoing and ever changing process. Under this form of analysis we will however have a way of understanding the healthcare system which is familiar to those operating within the system as either providers or receivers of care. From this starting point there flow a number of consequences for an analysis of healthcare systems.

First, none of us, neither patient nor clinician is in a position to discuss or describe the healthcare system, except from our own unique position within the system. At any moment we all have a specific position with regard to the system and we necessarily prejudge the working of the system from that position. The truth of this is most acutely illustrated when our position undergoes a radical change, most commonly the change we experience from being a provider of healthcare to being on the receiving end of care. The radical alteration of our position within the system of healthcare changes how we see the system in ways that we could not imagine before we became unwell. Under this kind of analysis we can see that it is essential, for the sake of hermeneutic completeness, that we appreciate fully and equally all of the perspectives held by all those who participate in the system including, and especially, those who receive care. As Gadamer will remind us, we are all, always “in play”, but this has even deeper consequences. It is the fact that we are “in play” that makes our analysis possible at all. If we did not have a position within the system we would have no perspective from which to discuss and give account of the system. Of course no-one who is concerned to give an account of the system can do so from outside the system because the system has no “outside” or “inside” and being “in play” is not a choice we can accept or deny. We all have an individual position with respect to the working of the healthcare system; the only thing that changes is the precise nature of our position. After all we are all patients or potential patients. This means that there can be no categorical account of the healthcare system, only one made up of

numerous subjective accounts all of which have their own value, both to those who provide them and to those who wish to understand the system. Again, from Gadamer on history we see that,

If we are trying to understand a historical phenomenon from the historical distance that is characteristic of our hermeneutical situation, we are always affected by history. It determines in advance both what seems to be worth enquiring about and what will appear as an object of investigation.⁶⁴

Gadamer's hermeneutic approach demands that we give up the futile attempt to find categorical objectivity and attend most closely to our own subjective experience. This is because understanding is only to be found in the interpretation of experience and the only experience we have is our own. In this way a host of interpretations develop based on the perspective of each individual; the validity of each interpretation is determined according to how well it fits the field of meaning which is generated by the entity in question, rather than any categorical definition of the entity. We do not need a categorical, ideal or objective definition of the healthcare system to enable us to distinguish between valid and invalid interpretations, we are able to understand and evaluate not only our own interpretation but also those of others from our position within the system. In this way we can retain the notion of the healthcare system as an ever changing scene while also retaining the ability to determine what is, and what is not, true about the system itself. The implications of this for healthcare systems and the way that they operate should be clear, and taking a person centered approach begins to look like a persuasive option because this is the approach which validates the interpretations of those in the system who are receiving care; in effect the perspective of those who give the system its most fundamental meaning. Healthcare systems only exist because there are people who need care.

Second, and following on from this, the healthcare system is not understood as any kind of thing. The encounters which make up the system continue every day and their nature may change as a result of changing circumstances. These changes may be intended or, more often than not

unintended, as individuals (persons and clinicians) make decisions about how they seek and deliver care with regard to a myriad of different factors. The healthcare system is a dynamic process which is in constant motion, it moves forward and changes as we speak. It is not just that we have a moving target when we come to consider the nature of the healthcare system, movement and change constitutes the system itself so our account needs to be dynamic and one which accommodates the ever changing narratives through which we understand the system.

Thirdly the meaning of the healthcare system can be found in each and every one of the millions of encounters that take place every day, as Gadamer says, “Every part expresses something of the whole of life—i.e., has significance for the whole—just as its own significance is determined by the whole”⁶⁵ Any analysis of an individual encounter will yield information about, and understanding of, the whole service, and *vice versa*. This means that we must not rely for our understanding of the system on large scale data analysis and the “big picture”. We cannot pretend that we are outside the system. Anecdotal evidence concerning the first hand lived experience of patients and clinicians (storytelling) is rehabilitated in our analysis and becomes at least as valuable as big data in giving us an understanding of the system at work. The lived experience of the ill person is placed at the centre of our understanding, not only of illness but inevitably of healthcare.

Fourthly, if the healthcare system is understood as the sum of all of the encounters then it can only be changed if the nature of these individual encounters is changed. No kind of organisational change can be effective which does not first and foremost begin with and have an impact on the individual encounters. This hermeneutic approach means that the focal point of the system must be the encounter between the person seeking care and the person offering care. In this sense the system is already person centered in that it depends for its reality and its meaning on the decisions and actions of persons on both sides of the encounter. They are the healthcare system at that time and place, as are all of the other persons

engaged in similar encounters elsewhere in the system. This in effect revalidates information and evidence that has previously been invalidated as merely subjective or anecdotal and places it back to the centre of our understanding of the nature of healthcare.

Overall a hermeneutic approach not only gives us an understanding of the healthcare system which is familiar to those who are in everyday engagement with the system, it offers a philosophical interpretation which is both robust and rich in terms of any analysis of the working of healthcare systems, and which points clearly to the ontological ground for person centered healthcare.

phenomenology = ontology = hermeneutics

To summarise the case so far, we can see how Heidegger's phenomenological approach combines with his own and Gadamer's hermeneutics to give us ontology. This is because,

Phenomenology, for Heidegger, is a method, its object is to let things show themselves as they are, and how they are possible (ontology). This means that only as phenomenology is ontology really possible.⁶⁶

In terms of our discussion of the philosophical basis for person centered healthcare we can see from Heidegger that a phenomenological investigation of illness and of healthcare will lead us to an ontology of illness and healthcare, indeed this is the only way that we can achieve this. If conducted phenomenologically our investigation will show us how these phenomena are possible and in so doing directs us towards the kinds of authentic ways in which we might respond to those who are unwell. In practical terms this means that we must attend to the specific individual experience of everyone involved in the healthcare system in order to gain an understanding. We must allocate a new priority to the experience of those who receive care; their account of their experience is unique and vitally constitutive of the whole system, to the extent that without it we

cannot ever understand the system and its workings. This is at least part of what we mean by person centered healthcare.

Heidegger also gives us a new understanding of our relationship with the Others we find in the world; we are not disconnected or distant from these Others. We are not simply there “with” them nor are they simply there “too”; our own Being is constituted by our relationship to these others to the extent that for the most part we exist as “they”. This kind of understanding is only possible when we accept Heidegger’s existential interpretation of Dasein, rather than seeking the categorical definitions of the post-Cartesian traditions. By re-framing, Heidegger’s interpretation dissolves the problem of Other minds. It remains to be seen whether or not we will be persuaded that his interpretation of Being-with-Others can provide a reason for any kind of behaviour towards Others, person centered or otherwise, and I will return to this question in Chapter Four in a discussion of Heidegger’s notion of solicitude.

Gadamer’s contribution to the argument is considerable. By emphasising the hermeneutical element of Heidegger’s interpretation of the Being of Dasein which begins and ends with everyday Being, he opens the way to an understanding of experience, world and, for our own purposes, healthcare systems which is philosophically rich, and yet familiar to those who are daily engaged in the system. The hermeneutical rule, in urging us to understand the detail in terms of the whole and the whole in terms of the detail, means that the unique anecdotal accounts of all of those engaged in the healthcare system gain a new and vital priority. To paraphrase both Heidegger and Gadamer, we must begin with the everyday experience of those who give and receive care and return to this everydayness our completed interpretations. In short, our approach must be person centered.

In the next Chapter I will consider the question, “What is the purpose of the healthcare system?” with the intention of beginning to show that this purpose can only be achieved through a person centered approach.

Chapter Three - What is Healthcare For?

Autonomy is the End of Healthcare

Having established the basis of the ontological relationship between different Others through Heidegger's notions of Being-in-the-world and Being-with-Others, and the setting out of Gadamer's hermeneutic approach and its potential application to healthcare systems, I now want to turn to the healthcare system itself and attempt to understand its purpose. By the end of this chapter, and using a phenomenological and existential approach to the questions at issue, I will show that the combination of our inescapable relation to Others, a hermeneutic approach to the understanding of healthcare systems, (which places the experience of those providing and those receiving care at the centre), and the affirmation of the restoration and preservation of personal autonomy as the purpose of the healthcare system, provides the philosophical ground for person centered healthcare.

I will argue in this chapter not simply that respect for patient autonomy is a fundamental principle of healthcare,⁶⁷ but that it is the main purpose of healthcare to both preserve and to restore (where it is absent) the autonomy of persons. The argument will be that respect for patient autonomy gains its fundamental place in healthcare practice because the main purpose of healthcare is to protect and restore autonomy. The result of this will be that the practice of person centered healthcare maximizes the independence of those who become ill. In all of this we must remember that the entity we call healthcare is not any kind of "thing" but the sum of all of the encounters which take place under the heading of healthcare. This hermeneutic understanding of the healthcare system will remain central to the discussion as characteristic of our understanding of the nature of the healthcare system. We are precisely *not* dealing here with an entity with any kind of fixed nature or essence, but a continuing activity in which we seek to find not a categorical definition but harmony between the whole and the parts, in this case the overarching purpose of healthcare and the individual acts of healthcare which constitute the system.

It is important at this stage to distinguish between two kinds of what we might call autonomy in order to avoid confusion at any later stage of the argument. When we encounter a doctor or other healthcare professional we voluntarily suspend our autonomy in the face of their expertise.⁶⁸ In this way we retain our freedom in the sense that Kant describes autonomy as the self-imposition of rules over ourselves.⁶⁹ This is quite different to the loss of autonomy that we experience when we fall ill. This loss is entirely involuntary and occurs before any encounter with healthcare services and is experienced by us as an interference in our autonomy from beyond ourselves. The difference is important because, in the first case (voluntary suspension of autonomy) we retain the freedom to choose and to act. In the case of illness (involuntary loss of autonomy) our freedom to act and decide is taken away from us by our illness, whatever may be the cause of the illness, or the kind of illness we are suffering from. We experience illness itself as an external constraint which we wish to see removed, usually with the assistance of some kind of healthcare professional. If our illness persists (for example in the case of chronic or degenerative illness) we eventually adapt to the new reality and make choices within the more restricted sphere of our being-unwell. It is our ability to choose and to act which makes us the kind of beings that we are and all the time that we are alive we retain our being-as-possibility or fundamental autonomy even when these possibilities are restructured by illness. Death is the end of the possibility of possibility, and thus the end of our being.

To summarise; we lose autonomy because of the illness, whatever that is. When we seek a therapeutic encounter (or in the case of severe mental illness when it is sought on our behalf) we suspend our autonomy for the period of the therapeutic intervention in the face of greater expertise (just as would an apprentice when learning from a master). This means that it is crucial that both parties to the encounter remember that this suspension of autonomy is temporary and is, overall, intended as a means to enable us to regain our fundamental autonomy which has been taken from us by illness. I will specifically discuss the encounter between healthcare professional and the person who is unwell in the next chapter, but for now we can return

to the argument that the maximization of autonomy is the fundamental purpose of all healthcare.

The force of the argument will lie in the connection between the extrinsic purpose of healthcare, the attempt to restore the autonomy which is lost when we become unwell, (in existential terms our ability to “do” as we “will”), and the practices which are intrinsic to healthcare (how we are cared for). I will argue that the process of healthcare, which has autonomy as its extrinsic purpose, must, if it is to be consistent with this purpose, operate in ways which respect the personal autonomy of those who are cared for in every aspect of healthcare practice. This is a specifically hermeneutic point in that we are here seeking harmony between the details of the system and our understanding of the whole, the harmony between the extrinsic purpose of healthcare and the intrinsic practice of providing care to each individual who needs it. In short, the intrinsic practice of healthcare must be person centered or risk contradicting its own purpose.

Before commencing with the substantive arguments to establish the preservation and restoration of autonomy as the purpose of healthcare we must be clear that healthcare is an activity with a purpose and not simply some random or meaningless human enterprise. I do not think that this requires much in the way of argument. Healthcare by its very nature is purposive since it is the activity of providing care to those who want and need it. It is clear that those who seek and receive care do so with an aim in mind, to get better; moreover, those who provide care are not indifferent to the outcome of their endeavour. The healthcare system understood as the totality of all of the continuing encounters between those who seek and those who deliver care can have a purpose only and because the activity of those engaged in it is individually purposive, that is, the outcomes of their actions matter to them. It is this mattering that makes the system what it is and makes it purposive. Healthcare has been described as “a complex clinical, human and moral endeavour”⁷⁰ and whatever else it may be it is an endeavour with a purpose. Gadamer affirms this purpose when he says,

The special quality of the art of healing, namely, that this act, unlike the arts for producing artifacts has as its task the restoration of something natural.⁷¹

He hints that this goal might be autonomy when he says,

Although health is naturally the goal of the doctor's activity it is not actually 'made' by the doctor. Connected to this is something further: the goal of health is not a condition that is clearly definable from within the medicinal art. For illness is a social state of affairs.⁷²

Thus he refers us beyond the field of disease and medicine and into the lives of the unwell, and their social being-with-others. It only remains then to determine the nature of this purpose, to do this I will first and briefly look at the importance of the idea of personal autonomy to our own self-understanding. I will then look at the ways in which illness diminishes and threatens our lives and the way that we then seek help from the healthcare system to restore our lost autonomy. The conclusion will be that, under this analysis, healthcare which is not intrinsically person centered defeats its own purpose and in so doing betrays our understanding of healthcare.

Autonomy

Autonomy means self-government, and is at the root of all that it is to be a human individual. The ability to determine our own destiny, to make choices against the background of circumstance, to be the author of our own life choices, is one of the most prized notions we hold about ourselves. We have only to think how we feel when we see this freedom to act threatened or see how others react when it is proposed to remove theirs. In saying this we are directly following Heidegger and Sartre⁷³ in the way that they both discuss and define freedom existentially, (the influence of Kant on both of these thinkers should also be acknowledged).⁷⁴ We are what we do and in choosing what we do we make ourselves who we are as Gadamer says,

For what fundamentally characterizes the essential constitution of human beings is that although their nature, just like that of any other living being, strives after fulfillment, what counts for them as fulfillment is not unquestioningly pre-established; rather they can set their own goals for themselves.⁷⁵

Strong cases for the importance of personal autonomy in general have been made by many philosophers, perhaps most notably Kant⁷⁶ and Mill.⁷⁷ I will not set out these cases here since to do so would distract from the flow of the specific discussion of healthcare. I am well aware of the power of these arguments and, even unstated; they provide a backdrop to the argument that the restoration and protection of autonomy is the fundamental purpose of healthcare.

In the case of our understanding of illness and the purpose of healthcare, and consistent with the existential approach, I will consider here more the nature of actual autonomy, as Agich says, “Actual autonomy is not best understood in terms of decisional modes, but in the daily ebb and flow of action and experience”⁷⁸, and Trotter puts it well when he says,

Autonomy as self-sovereignty is the quality of living in accordance with one’s inner nature or genius. A condition for autonomy as self-sovereignty is living apart from, or in defiance of, powers that compel one to forfeit or exchange quantities of life for “goods” that one does not recognize as such, or does not recognize as worth the exchange.⁷⁹

It is this “quality of living in accordance with one’s inner nature” that we lose when we become unwell and the same quality of living that we look to be restored by healthcare. We need therefore to understand what precisely it is that we have lost and what we are hoping that those providing healthcare will restore. From a personal point of view, and in order to understand the nature of this loss, we need first to understand what happens to us when we fall ill and the relationship between being ill and being healthy. I will consider this under four related headings, these will be: the nature of the loss which we experience in illness, suffering, alienation, (or the sense we have of not-being-at-home when we are ill, and equilibrium (as in the disturbance of the balance of our lives). To some extent these distinctions are arbitrary, and the connections will at times be recognizable in each separate consideration. I will finally argue that all of these relate to, and constitute together, a fundamental loss of autonomy in illness and one to which all healthcare, whatever its immediately apparent purpose, responds.

Loss

When we fall ill we experience a loss and although we may characterize, or be characterized by others, as having gained something (an illness), it does not feel like this. Loss is one of the most significant ways in which we ourselves experience our being-unwell. We do not notice the addition of a disease rather we are called towards the loss of bodily functions which had previously carried on unnoticed. Amongst the many narratives of illness I want to briefly consider only two under this heading of "Loss". Havi Carel and S. Kay Toombs both suffer from progressive and degenerative conditions⁸⁰ and both have engaged in extensive philosophical reflection about their experience of illness, both therefore provide the kind of first-hand accounts of their experience which is in accord with our phenomenological existential approach.

For both of these women, illness is at least in part a matter of loss of bodily function. This is summed up by Carel when she says, "In illness the biological body comes to the fore, as it ceases to cooperate with the ill person's desires."⁸¹ This focus on loss of autonomy has consequences for healthcare and as Toombs points out,

Such insights have practical application in the clinical context. Indeed, if therapy is to be successful, it is essential to address the global sense of disorder that permeates the patient's everyday life.⁸²

If we continue with the existential style of analysis we can say that illness is experienced as the inability to do things that we have been used to doing; a gap opens up between our willed existence and our biological existence. We can no longer do the things that we will. In illness this is experienced as a sudden, or relatively sudden, loss of ability to act as we will, while in ageing the loss is more gradual and therefore less noticeable. In both cases (illness and ageing) the loss is a loss of personal autonomy. Gadamer puts the general point about loss of function very well when in a style reminiscent of Heidegger,⁸³ he says, "it is only in its absence, that I notice what was previously there, or, more precisely not *what* was previously there but *that* it was there."⁸⁴ For Carel the experience of loss is more personal so that,

The bodily foundations of autonomous adulthood are often removed, revealing the tentative and temporary nature of these foundations. Illness can disclose and make salient finitude, disability, and alienation from one's body as extreme modes of being.⁸⁵

In the case of illness when this loss becomes more than we can manage, and at this stage pain is often the trigger, we consult someone with expertise in healthcare as a means of seeking the assistance we need to restore our previously experienced autonomy. For example, when I injure my leg while gardening I find that I am unable to cycle (it hurts!). If after a few days, and when I really want to cycle again and my leg will still not let me (it still hurts), I go to the doctor to find out what is wrong and how it can be fixed so that I can resume my previous level of autonomy and go cycling again. Of course there are many more varied and complex scenarios that occur every day in every healthcare system but all of them, however complex and varied, conform in essence to this basic analysis of loss and attempted restoration of autonomy. Carel expresses this in philosophical terms when she says,

The body responds to the environment in an ongoing dialogue. Everything else depends on the body's ability to perform, predict and react appropriately to stimuli. The body is the core of our existence and the basis for any interaction with the world.⁸⁶

Illness represents the interruption of this dialogue and constitutes a threat to our existence as an existential being so that,

Illness is not simply a problem in an isolated physiological body part, but a problem with the whole embodied person and her relationship to her environment. Because the lived body is not just the biological body but one's contextual being in the world, a disruption of bodily capacities has a significance that far exceeds that of simple bodily function... It is not just a body function that is disrupted. Rather an entire way of being in the world that is disrupted.⁸⁷

To this extent the loss we experience in illness is the loss of ourselves.

Toombs gives a vivid account of her loss of autonomy when she becomes ill with multiple sclerosis, she says, "my illness is the impossibility of taking a walk around the block or of carrying a cup of coffee from the kitchen to the den"⁸⁸, and then with reference to a wider loss of personal autonomy,

Loss of upright posture not only concretely diminishes one's own autonomy (as a person who routinely uses a wheelchair I have no choice but to request assistance in a world designed for upright bodies) but it causes others those who are still upright to treat one as dependent. Whenever I am accompanied by an upright person, in my presence strangers invariably address themselves to my companion and refer to me in the third person.⁸⁹

While this is one of the more extreme case of loss of autonomy it represents the more general disruption that we all experience when we become unwell, as she says,

The disruption of this unified body/world system also includes the disruption of the body as intentional locus. Surrounding objects that were formerly used unthinkingly are now encountered as overt problems to the body.⁹⁰

Loss is not localized. Illness, by changing what we can do, changes who we can be. In the case of the minor and self-limiting illnesses which plague all of us throughout our lives the change is temporary and short lived. We are soon restored to our full ability and take up once again our place in the world. In the case of serious illness, and particularly in the case of chronic illness, the loss cannot be fully restored and we have to “learn to live with it”. We are changed forever and “not-being-able-to-do” becomes part of who we are. I understand this only too well from my own experience of chronic illness and life changing surgery. We live, and mourn our loss, but we learn to be who we have become, and we look to those who provide healthcare to assist us in this task.

Both Havi Carel and S. Kay Toombs are philosophers living with progressive and degenerative diseases and it is clear from what they say that loss is a constant feature of their lives as their health deteriorates. While both of these cases present examples at the extreme of loss through illness, they vividly illustrate what happens to us in terms of loss of function when we become unwell, and the way that this loss changes their lives. Gadamer recognises this when he says of doctors who have thought about it,

The most fundamental challenge which faces them is not simply to aid the recovery of the person who is sick. Rather they are confronted with the challenge of restoring to patients their own sense of self-identity by enabling them to return to and take up again their own particular way of life and to exercise their own particular abilities.⁹¹

The loss that we experience when we fall ill is a loss of autonomy and, because of the centrality of the notion of autonomy to our sense of who we are as what we are able to do this loss constitutes a very real threat to our existence, both materially and ontologically. Person centered healthcare responds to this loss by supporting the maximisation of autonomy.

The Case for Suffering

The amelioration and alleviation of suffering is naturally held to be at least one of the purposes of healthcare and while I will not contest this belief I think that it can be quite simply shown that the relief of suffering is one aspect of the attempt to preserve and restore autonomy and that the relief of suffering can therefore be subsumed under the overall desire to preserve and restore autonomy.

As I mentioned above it is often our suffering pain which precipitates us into a formal state of illness. We make public our feeling unwell perhaps by admission that we cannot go to work or attend a social function, or eventually when we present with our symptoms to the doctor. Svenaeus says that, “pain is a feature of my intentional bodily being.”⁹² And at more length,

Illness makes us feel our own bodies: it reveals the body to us in different ways, through making it heavy, stiff, hot, nauseated, plagued by pain, twists, jerks, shivers, etc.⁹³

It is indisputable that the experience of illness is an experience of suffering, this much is clear to any of us who have experienced the pain and discomfort of illness, but suffering is more than just pain,

‘Suffering’ is understood as fundamentally different from ‘pain’ in that the entity experiencing it is a *person*, not merely a *body*. More specifically, ‘suffering’ occurs when forthcoming destruction of one’s *personhood* is perceived and continues until the threat has passed

or the integrity of the person is restored in some other way. It is ultimately a personal matter: its presence and extent *can only be understood by the sufferer*.⁹⁴

This explanation is both existential and phenomenological and it connects the suffering of the person in illness to a kind of loss of autonomy in much the same way as loss of capacity is seen as a threat to the existence of the human individual as a 'being-able-to' "set their own goals for themselves".⁹⁵ When we suffer we suffer a threat to our individual integrity. As Carel puts it right at the beginning of her book *Illness*, "The first time I realized I couldn't do something I felt surprise. It came as an insult."⁹⁶ This is further emphasized by Yelovich when she cites the example of the ballet dancer who suffers from the breathlessness of asthma but who suffers even more when the optimal treatment for her asthma so disrupts her physical capacity that she can no longer dance. From the treatment, given as result of her illness, she suffers the loss of her ability to dance; "she didn't live just to breathe, but breathed so that she could dance".⁹⁷ In terms of her specific disease (asthma) her suffering was alleviated by the treatment, but this left out of account her being as a dancer and she then 'suffers' the loss of her ability to do that which makes her who she is. The case arises because the doctor treating her does not understand the individually specific nature of suffering and treats her as a case of asthma, rather than in a person centered way as a ballet dancer with asthma. As Yelovich makes clear,

Although the 'pain' experienced by two thirty-five year old men who permanently lose the use of their left hand in the same way may be the same, the 'suffering' experienced by the sculptor will almost certainly exceed that experienced by the telephone insurance salesman, all other things being equal. 'Suffering' is not limited to the physical symptoms, but is mediated by patient meaning. "Most generally, 'suffering' can be defined as the state of severe distress associated with events that threaten the intactness of person."⁹⁸

Once again this links the experience of suffering with the nature of our individual Being as being able to set our own goals. At the root of our suffering is some kind of removal of capacity either through simple pain or some other aspect of our being unwell. Svenaeus goes further and says,

From a phenomenological point of view one could say that in many cases of suffering, and significantly, in the cases connected to pain and the other bodily ailments mentioned above, the 'lived body'—the body as a person's way of existing and doing things in the world—displays an alien character in showing up as an obstacle and a limitation instead of as an affordance and possibility in life.⁹⁹

This character as obstacle denotes the loss of autonomy that we experience in the suffering brought about by illness; this is made even more explicit when he says, "pain unmakes the world of the person"¹⁰⁰, and then,

But pain does not stop at the sensation level of presenting the body as a troublesome and torturous alien; as a mood, it also affects the person's ways of living in a world of human goals and projects. It does this by way of presenting the world in a new alien tonal-colour and in preventing our everyday doings through offering new and alien resistance, as I mentioned above. It can be a challenge to take a walk, climb the stairs, or wash the dishes when the body aches and refuses to perform in habitual ways, not to mention staying focused in a conversation at the workplace or playing soccer with the kids.¹⁰¹

The effect of pain and suffering is to limit our possibilities and although suffering in illness is usually first manifested when we feel pain or discomfort what we are really beginning to experience is a loss of capacity and ultimately loss of autonomy. Our stride through life is interrupted by illness and the pain that we suffer is just the precursor of the restriction on our activity that illness will bring. If we are fortunate we will recover and the sign that this has happened is the cessation of pain and discomfort, which itself leads to a recovery of capacity. Our suffering is ended, and we continue as before.

In the case of chronic illness suffering takes on a permanent role in our lives and we are never able to return to our activity as before so that, "In the chronically ill the orientation necessarily shifts from the removal of the cause of suffering to the suffering itself, since the suffering attacks the core of identity."¹⁰² Chronic illness is different because it persists and with it persists the suffering so that,

With the chronically ill patient managing the illness is coincident with managing one's life. That is illness does not exist as some independent thing to be managed but as an element or factor in a common negotiation with the world. This means that chronic illness

involves a suffering that is far more subtle and pervasive than merely being made passive by an episode of acute illness.¹⁰³

It is in the example of chronic illness that suffering is revealed at bottom as loss of autonomy so that the relief of suffering represents a restoration of autonomy. In chronic illness we suffer a permanent loss of capacity, and if the illness is degenerative and progressive we suffer continuing loss. The suffering becomes a part of who we are and who we become because, “In chronic illness one undergoes the illness not as an intrusion into one’s life, but as a way of life”¹⁰⁴ When we suffer chronic illness we suffer a permanent loss of capacity, an end to the way of life we had before we became ill, and the beginning of a life of reduced autonomy.

Having established links between loss of capacity and loss of personal autonomy, and between the notion of suffering and loss of autonomy I will now look briefly at the idea that in illness we are precipitated into a state, or mood, of feeling not-at-home in our lives and show that the key to understanding this mood is as a loss of personal autonomy.

Illness as Unhomelike Being-in-the-world

The expression ‘unhomelike’ or ‘*unheimlich*’ is used by Heidegger in his interpretation of the everyday being of Dasein. It is the feeling we experience when we are abruptly removed, in the mood of anxiety, from our everyday preoccupations with the world to face the possibility of our own authentic being.¹⁰⁵ In anxiety we are brought up short before the truth of our being, shaken out of the comfort of our everyday being.

Anxiety individualises Dasein and discloses it as *solus ipso* ... what it does is precisely to bring Dasein face to face with itself its world as world, and thus bring it face to face with itself as Being-in-the-world.¹⁰⁶

And,

Anxiety makes manifest in Dasein its *Being towards* its ownmost potentiality-for- being—that is, its *Being-free* for the freedom of choosing itself and taking hold of itself. Anxiety brings Dasein face to face with its *Being-free* for the authenticity of its Being, and for this authenticity as a possibility which it always is.¹⁰⁷

Most of the time we evade anxiety, we remain preoccupied with our everyday existence in the comfort of the at-home, but as Heidegger goes on to say,

When in falling we flee *into* the “at home” of publicness, we flee *in the face* of the “not-at-home”; that is we flee in the face of the uncanniness which lies in Dasein—Dasein as thrown Being-in-the-world, which has been delivered over to itself in its Being. This uncanniness pursues Dasein constantly, and is a threat to its everyday lostness in the “they”, though not explicitly.¹⁰⁸

This means that, “*the not-at-home* must be conceived as the more primordial phenomenon”¹⁰⁹, and that our everyday way of being (the at-home) itself rests on, and is made possible by, the uncanniness that we experience when we understand our own being-in-the-world. We can only be ‘lost’ in everydayness if we have the possibility of finding ourselves. In illness the progress of our life is interrupted, and we face not only the possibility of our own Being-authentic but our own finitude. When we fall ill the uncanniness which pursues us catches up and we are brought up short and shaken out of our complacent and comfortable life. As Svenaeus puts it,

A disease, at least a severe one, is indeed something which breaks in on us and destroys us. Such phenomena, according to Heidegger, resist meaning; they are even an offense to our attempts to find a place for them in our life as a meaningful whole. They strike against us as something totally unfamiliar, which threatens our existence.¹¹⁰

And,

The life-world is usually our home territory, but in illness this homelike being-in gives in and takes on an un-homelike character, in which the otherness of the body addresses us in a threatening way. It is the mission of health care professionals to try to understand such un-homelike being-in-the-world and bring it back to home-likeness again, or, at least, closer to home.¹¹¹

The life world that Svenaeus refers to is the life in which we are free to choose and in which we are in tune with our bodies. It is exemplified in the harmony between will and ability. We will and act in a seamless continuity

until this continuity is broken by illness. In illness we are out of tune with our bodies and we miss the homelikeness of good health. This experience is familiar to anyone who has ever received a diagnosis of serious illness; the effect is traumatic and prompts us to a complete re-assessment of our lives.¹¹² Even if we are able to recover from illness we are forever affected by the trauma of illness and our outlook on life is changed. We experience the everyday life that we have recovered in quite another way and we appreciate the simple freedoms that others may take for granted, and that we certainly took for granted before we were ill. Illness prevents us from doing the things that we usually do and when this happens we feel not-at-home in our bodies, even to the extent that we try to deny that we are ill at all. We attempt to alienate ourselves from our malfunctioning bodies hoping that illness will just go away; we pretend that we are not ill. Eventually, and however much we try to flee, illness catches up and we are faced with the uncanny, specifically the possibility of the end of the life that we know, and in the case of serious illness, the end all of our possibilities, the end of all our projecting and of all of our choosing. The implications for those who try to treat us become clear.

Health care professionals must also address everyday life matters of patients with a phenomenological eye, addressing and trying to understand the being-in-the-world of the person's life, which has turned unhomelike in illness.¹¹³

In terms of the relationship between this feeling of not-being-at-home and the loss of personal autonomy the connection is clear. The way that we experience this unhomelike feeling is first through the pain and discomfort (both physical and mental) that illness brings, and then through the ways that this prevents us from carrying on with our everyday lives, lives which are full of choices, some of which we are now unable to make because,

Illness is an unhomelike being-in-the-world in which the embodied ways of being-in of the self (person) have been thwarted. In illness the body shows up as an alien being (being me, yet not me) and this obstruction attunes the entire being-in-the-world of the ill person in an unhomelike way.¹¹⁴

This understanding of illness and the quality it has of alienating us from our own bodies and making us feel not-at-home once again re-enforces the centrality of personal autonomy. In our ill and alienated state we are unable to do the things that we usually do. These are the things that not only make up our lives but which make us who we are. The restoration to a state of being-at-home with ourselves is the restoration we seek when we seek medical help, and this restoration is manifested when we are able to return to the things that we did before we were ill, in the seamless flow of willing and doing that makes up our everyday lives. In Heidegger's terms we are restored to the everyday but with an understanding of the uncanny and our own finitude which remains with us. We understand our own possibility for being-authentic. This is the reason why people who have recovered from serious illness see their lives differently, once we have experienced the feeling of not-being-at-home we can never forget.

I will now consider one further understanding of health and illness as a matter of balance or equilibrium this is given by Gadamer in his book of late essays, *The Enigma of Health*.

Health as Equilibrium

Gadamer's first point is that doctors do not create health, "Although health is naturally the goal of the doctor's activity it is not actually 'made' by the doctor."¹¹⁵, this is because, "The special quality of the art of healing, namely, that this art unlike the art for producing artefacts has as its task the restoration of something natural."¹¹⁶ We are thus left to consider what it is that is 'natural' that Gadamer expects to be restored by healthcare. The answer from Gadamer begins like this,

It is obvious that the art of healing occupies an exceptional and problematic position. For here there is no 'work' produced by art and no 'artificial product'... it belongs to the essence of the art of healing that its ability to produce is an ability to re-produce and re-establish something.¹¹⁷

The aim of healthcare according to Gadamer is the re-establishment of a kind of equilibrium so that,

The expert practice of this art inserts itself entirely within the process of nature in so far as it seeks to restore this process when it is disturbed, and to do so in such a way that the art can allow itself to disappear once the natural equilibrium of health has returned.¹¹⁸

For Gadamer illness has the nature of loss of natural equilibrium and in this we may hear echoes of the *unheimlich* from the work of Heidegger and Svenaeus. When we become unwell we are thrown off balance and in seeking healthcare we are seeking someone who can restore this balance. Loss of balance is an interruption of the smooth course of our lives and as a metaphor for what we feel when we become ill, and in particular when the illness is serious. It rings true, as Gadamer goes on to say,

We encounter the recovery of equilibrium in exactly the same way as we encounter the loss if it, as a kind of sudden reversal. Properly speaking there is no continuous and perceptible transition from one to the other, but rather a sudden change of state... What we encounter here, by contrast, is the experience of balance.¹¹⁹

When we recover from illness we regain our balance and, in the event of cure, we are able to continue with the kind of life we had before. We recognize when this happens when we are able to recommence making the everyday choices that we are all used to making and which illness makes difficult or impossible. However, this does not mean that there is only one possible state of equilibrium, incomplete recovery, or the steady loss of capacity that we experience as we age, necessitates continuous rebalancing and the finding of one new state of equilibrium after another. This means that the role of the healthcare worker, which as he has already pointed out, is not to produce anything but to restore something that is missing, becomes one of constant balancing and re-balancing our lives to the extent that,

The consequence to be drawn from this is that medical practice is not concerned with actually producing equilibrium, that is with building up a new state of equilibrium from nothing, but rather is

always concerned with arresting and assisting the fluctuating equilibrium of health.¹²⁰

In all of this Gadamer is seeking to emphasize the experience of illness as central to our understanding of what it is to be well and what it is to be ill. His analysis is both existential and hermeneutic and focuses on the real individual who is unwell and who has lost equilibrium.

Sickness and loss of equilibrium do not merely represent a medico-biological state of affairs, but also a life historical and social process. The sick person is no longer simply identical with the person he or she was before. For the sick individual 'falls out' of things, has already fallen out of their normal place in life. But the individual who now lacks and misses something previously enjoyed still remains orientated towards returning to that former life.¹²¹

The consequences for healthcare under this form of analysis are clear. It is the business of the doctor to attend to the restoration of equilibrium in the person seeking their help. We look to doctors to restore our equilibrium so that we can continue with our lives after the interruption of serious illness, or while we carry the burden of chronic illness. The life we wish to return to is not necessarily the one that we had before. Illness changes us and we can never be the same again. But whatever else it may turn out to be the life that we wish to return to is the life of choosing and deciding for ourselves about the things that we do, even when this choice is continually restricted by chronic illness. As patients, and as people who are experiencing loss of balance, we have lost control of our lives; the restoration of some kind of balance makes us able once again to resume the setting of goals for ourselves. The restoration of equilibrium becomes the restoration of the autonomy that makes us who we are. Once again the task of the healthcare worker in restoring equilibrium becomes the task of restoring autonomy.

Autonomy in Healthcare

Two important conclusions arise from all of this. First it is me who decides when to seek help. I take the first and most important decision to take my body to the doctor to see what is wrong and to get it fixed. When I see the

doctor I decide what to tell her and when I receive her advice I decide how much notice to take. This is not only true of the simple patient/doctor scenario; it remains true throughout any period of consultation and treatment that I may engage in as part of the attempt to restore my autonomy. My engagement in this process is itself an expression of my autonomy. At all stages of the process it is me, the person who is ill, who takes all of the important decisions. I am never, and never can be, a mere object in this process. For me to agree to become such an object, or for others to behave as if I am, contradicts the very purpose of my own enterprise in seeking help to restore my lost autonomy, and of the enterprise of those who offer assistance to me in this endeavour. Personal autonomy is vested in self-conscious subject, not in objects. Lost autonomy cannot be restored in a process that does not treat me as an autonomous subject and I will experience any such process which attempts this as self-defeating. The contradiction that I experience is grounded in the lack of harmony between the extrinsic purpose of healthcare and intrinsic practice which contradicts this purpose.

The second conclusion is that my illness is always presented and seen in the context of my life as a person. My illness is not separate from me; it occurs within the context of my lived experience (life) and is only relevant within that context. If the process of consultation, advice and treatment that I experience when I seek help tries to separate, in any way, my life from my illness then it has failed to understand the reason why I am seeking help in the first place. In medical training this is usually understood by the dictum, “treat the patient not the disease” and the fact that so many have to be reminded so often by this dictum is an indicator of how far modern healthcare has strayed from treating persons to making us all into patients. Without the context of my life my illness has no meaning, (like the ballet dancer with asthma). As a person who is ill I remain conceptually at the centre of my care. This is perhaps why it has been asked why we even need to specify “person centered healthcare”. We should not need to state the obvious and the fact that we do need to shows how far behind we are leaving persons in modern healthcare.

This leads to two simple precepts. First; that health and healthcare can only be understood and practiced when illness is understood in the context of the life of the person who is ill, and that any healthcare practice that attempts to separate persons from their illness is bound to fail. Even when we are ill we still have a life and it is always a mistake for others (and sometimes we ourselves) to define us by our illness. Illness may be an interruption in the course of our lives but it remains a part of our life.

Second; that healthcare is provided with the aim of restoring autonomy to people who have lost or are losing autonomy. This aim is not always realized; sometimes the loss of autonomy continues and ends in death. On other occasions autonomy may be partially restored and we adjust our willing to the new biological reality. More often than not, in the myriad of simple cases that we and our doctors face every day, autonomy is fully restored. Autonomy, or the potential for autonomy, is the way in which we recognize each other and ourselves as human individuals and in all cases the underlying aim of healthcare should be the restoration and preservation of the personal autonomy of the people who seek help. Healthcare that does not have respect for autonomy at its core cannot ever meet its own aims, and must forever contradict its own purpose.

In the next chapter I will consider in more detail the relationship between those who seek care and those who provide it and through this the things that I consider to be the obstacles to person centered healthcare.

Chapter Four - Persons and Patients - Solitude and the Person/Clinician Dialectic

In this Chapter I want to have a look at the process of becoming a patient and remaining a person. To do this I will extend and deepen the discussion from Chapter Two about our relationship towards Others like ourselves. I will also consider the dialectical nature of the relationship between patients and doctors (and everyone else who treats us) and try to understand how this points towards the conclusion of a person centered approach to healthcare. Following this discussion I will offer a couple of practical examples of what person centered healthcare might look like in practice.

Solicitude

Heidegger describes the specific ontological relationship we have towards other Dasein with the term “solicitude”.¹²² This is different from the term “concern” which he uses to describe our ontological relation towards all of the other entities that we find in the world, for example chairs and desks, and different again from the way he interprets the meaning of Dasein as “Care” when setting out the everyday being of Dasein.¹²³ While in English translation these terms are clearly distinct, their German origins give us the theme which connects them in Heidegger’s thought. The translations are; for solicitude, *Fürsorge*, for concern, *Besorgen*, and for Care, *Sorge*.¹²⁴ All three terms are rooted on the same German notion of *Sorge*, meaning care in the sense that we are concerned with them in our everyday lives, of mattering to us, as the way in which we find ourselves necessarily and inextricably engaged within a world of entities and Others like ourselves. It is in this sense that the conception of an isolated subject makes no sense. We cannot conceive of ourselves as existing alone in a world without Others. From the German originals we see that both concern (*Besorgen*) and solicitude (*Fürsorge*) are manifestations of the Being of everyday Dasein as Care (*Sorge*).

This means that when we are considering the relationship of solicitude that we have towards Others like ourselves we are doing so within the existential analysis of Dasein as whole. Our Being-with-Others is an aspect of this whole, so that “Even concern with food and clothing, and the nursing

of the sick body, are forms of solicitude.”¹²⁵, and with direct relevance to the idea of person centered healthcare, “For example ‘welfare work’, as a factual social arrangement is grounded in Dasein’s state of Being as Being-with.”¹²⁶ However, “With regard to its positive modes solicitude has two extreme possibilities.”¹²⁷ The first of these takes away ‘Care’ from the Other it *leaps in* for him so that,

This kind of solicitude takes over for the Other that with which he is to concern himself. The Other is thus thrown out of his own position; he steps back so that afterwards, when the matter has been attended to, he can either take it over as something finished and at his disposal, or disburden himself of it completely. In such solicitude the Other can become the one who is dominated and dependent, even if this domination is a tacit one and remains hidden from him.¹²⁸

This is a vividly reminiscent of the kind of paternalism which has historically been a prominent feature of healthcare. But,

In contrast to this there is also the possibility of a kind of solicitude which does not so much leap in for the Other as *leap ahead* of him in his existentiell potentiality-for-Being, not in order to take away his ‘care’ but rather to give it back to him authentically as such for the first time. This kind of solicitude pertains essentially to authentic care—that is, to the existence of the Other, not to a “*what*” with which he is concerned; it helps the Other to become transparent to himself *in* his care and to become *free* for it.¹²⁹

This sounds like what we are talking about when we talk about people who fall ill and who are helped to recover their independence by healthcare services. They become patients when they fall ill and are returned to full personhood by the provision of authentic care. This is the person centered approach that we hope will create persons who, although they may still be ill to some degree, are what is termed “self-managing”.

In terms of an approach to the provision of healthcare, and following Heidegger, we appear to have two alternatives. The permanent objectification of the person receiving care, which will encompass all cases up to and including patient centered care, and which crucially fails to understand the primordial relationship we have with Others; and authentic solicitude, in which relationship the humanity (ontologically speaking) of the

person receiving care is recognised and placed at centre stage. We call this person centered care. Authentic solicitude is the approach which frees the Other rather than seeks to dominate and the approach which is in accordance with the purpose and meaning of healthcare itself.

A Short Digression with regard to Empathy

Havi Carel says, “There are many terrible things about illness, the lack of empathy hurts most.”¹³⁰ If this is the case empathy is clearly an important notion so, before going on to close the circle of this part of the work, a short digression on the subject of empathy will illustrate how Heidegger’s phenomenological ontology works in practice, and show us where the idea of empathy stands in relation to our understanding of illness and healthcare.

Empathy is often seen as a key part of both effective healthcare and person centered healthcare and it is from this basis of solicitude that Heidegger is able to approach the notion of empathy.

‘Empathy’ does not first constitute Being-with; only on the basis of Being-with does ‘empathy’ become possible: it gets its motivation from the unsociability of the dominant modes of Being-with.¹³¹

Heidegger does not expand on the notion of empathy in *Being and Time*, but the direction of travel is evident from what he has said about solicitude. Svenaeus, following Heidegger, says that, “Empathy in this way is a kind of discernment, a way of seeing what is going on in a world that we share with other human beings”.¹³² Agosta takes Heidegger’s beginning and provides a more extensive interpretation of empathy. He says,

Optimally, in empathic receptivity one experiences a trace, a sample, a vicarious representation, of the other’s experience of suffering, joy, or indifference, so that one “gets it” experientially and emotionally as well as cognitively.¹³³

It is not simply a matter of seeing the signs of, or recognising the experience of the Other in ourselves, in empathy we have to “get it” experientially in a way separate from our deliberate and detached cognition. The Heideggerian interpretation thus remains distinctly

existential and outward looking towards the Others we find in the world. This means that Agosta can say that,

empathy is the capacity that enables the one person to humanize the other individual by recognizing and acknowledging the possibilities for growth, transformation, healing, and recovery in the other.¹³⁴

Empathy is a capacity, or as Heidegger might have said empathetic behaviour is an authentic possibility of Dasein. This points us towards an ontological understanding of empathy as the basis for person centered healthcare. In empathy our fundamental relation to Others is called forth so that,

empathy is fundamental to being with others, and its withdrawal or absence is a crisis that calls into question one's relatedness to other individuals that renders individuals and communities vulnerable to breakdowns that are dreaded as much (and sometimes more) than death itself.¹³⁵

This interpretation of the nature of empathy propels us to a person centered approach to healthcare in that it bids us, from the depths of our being, to respond to those who need help. To ignore their plight becomes an act of denial of our own deepest ontology. The response of empathy is itself predicated only on the basis of Dasein's fundamental Being-with-Others and the relationship of solicitude we have towards these others, so that being-empathetic becomes a possibility for Dasein, and an authentic possibility at that. In contrast a failure to show empathy can then be understood as a failure to respond authentically, as a failure to recognise the Other as Dasein or "one like me", so that,

Overlooking vicarious experience in the hermeneutic circle of empathy results in a misunderstanding that grasps only the cognitive dimension and reduces the process of empathy to an over-intellectualized "putting one-self in the other's shoes." While there is nothing wrong with "jump starting" empathy by imagining the pinches and discomforts of walking in the other's shoes, there is something missing—namely, receptivity and the dimension of affectedness, corresponding to *Befindlichkeit* (*state-of-mind*).¹³⁶

The response must remain personal, existential, and to some extent emotional. We are concerned here with what Heidegger calls state-of-mind and it is the way that we approach the Other that determines whether or not we are being empathetic rather than what we actually do. In the case that Havi Carel refers to two nurses treat her on separate occasions, both perform the required tasks to the required standards but it is the difference in their attitude to her, one empathetic the other not, which highlights the importance of empathy and it is the lack of empathy shown by one nurse that leaves her distressed and in tears.¹³⁷ I will discuss this example again along with more of Carel's work in the next chapter but the central role of empathy in healthcare is surely summed up by Svenaeus when he says,^{138,139}

Empathy is actually a capacity making the doctor more able to make a correct diagnosis, and also a quality of the medical meeting that contributes to empowering patients and improving upon their recovery.¹⁴⁰

This means that

Patients who feel that their doctors care for them and attempt to understand and help them will often be satisfied even if there is nothing to be done, or even if the doctor does not do the right thing for them. This is a clear proof of how powerful the feelings of empathy (and the lack thereof) and the dialogues between persons that empathy enables (or precludes) in medicine are.¹⁴¹

Empathetic behaviour on the part of the doctor, or nurse, promotes the ends of healthcare and is manifested in the person centered nature of the practice of the particular doctor or nurse, there is harmony between extrinsic purpose and intrinsic practice. In this sense of empathy, being empathetic in approach means being person centered in practice

A lack of empathy denotes no more or less than a mistaken interpretation of the nature of our own Dasein and that of Others. The possibility for empathy is just part of who we are; it is up to us to determine how we respond to the empathetic impulse in our relations with the Others that we find ourselves inextricably bound up with in the world. We can choose to

be inauthentic or to endeavour to realize our authentic possibility. As Agosta so eloquently puts it,

a special hermeneutic of empathy in the spirit of Heidegger is not humanism, it is a clearing for the possibility of being human; it is not existentialism, it is the clearing for the possibility of human possibility; it is not ethics, it is a clearing for respect, integrity, altruism, and a recognition of who is one's neighbor that expands one's humanness; it is not psychotherapy in the narrow sense, it is a clearing for human interrelatedness in the context of an inquiry into being human that unmasks inauthentic behavior and relieves emotional distress; it is not aesthetics, it is a clearing for the communicability of affect; it is not rhetoric is a clearing for being effective through language; it is not parenting, teaching, or leadership, it is a clearing for a commitment to community, making a difference, and improving the quality of life.¹⁴²

An authentic or empathetic response would be a response which fully recognised the ontological reality of different Others and our relations towards them. It may also be seen as a response which would point towards person centered care. On the other hand what Heidegger might call an "unsociable" response would be a response which was based on a mistaken understanding of the nature of the Other and of our own Dasein as Being-with-Others. This will lead us to paternalism or, even worse, a complete de-personalisation of care. Because of the way that the being of the Other is constitutive of our own being the denial of the nature of the Other includes a denial of our own being.

While we live our everyday lives in the inauthentic modes of Dasein, including *Being-they*, we retain an understanding of authentic Dasein and what it means to be human, and we remember that this is the foundation of all of our Being, including inauthentic Being, like this,

Being-with is such that the disclosedness of the Dasein-with of Others belongs to it, this means that because Dasein's Being is Being with, its understanding of Being already implies the understanding of Others. This understanding, like any understanding is not an acquaintance derived from knowledge about them, but a primordially existential kind of Being, which more than anything else makes such knowledge and acquaintance possible.¹⁴³

Or as Guignon puts it, with admirable clarity,

To be human in Heidegger's view is to be a place holder in a network of internal relations, constituted by a public language, of the communal world into which Dasein is thrown.¹⁴⁴

We can choose the nature of our place-holding but we cannot choose not to have a place, and the place we inhabit includes Others like ourselves. I will return briefly to the notion of empathy later in this chapter under a consideration of the specific relationship between doctors and those that they treat and after a discussion about what happens to us when we become a patient.

From Persons to Patients

Something happens to us when we go and see a doctor or some other kind of healthcare professional. We go along as an independent thinking person who has made a decision to seek help with a health problem. We enter the room as an autonomous subject and leave, more often than not, as a patient. As Sayers says,

When a person becomes a patient a change occurs, both in the way the individual regards his or her self, and in the way in which others regard the person. Yet, there may be no externally visible signs of illness and so, analogously, there could, on the face of it, be two apparently identical representations of the individual; the prior well self and the current patient self.¹⁴⁵

What is it that happens during this brief encounter? What is it about the nature of the encounter that changes us from being a person to being a patient?

We may argue that the change is not permanent and when we emerge and go back to our normal lives we become persons again, and this may at first appear to be the case. In fact we are changed forever, even after the encounter our decisions and actions are influenced and sometimes dictated by what happened. We are now a patient acting on the advice of someone who knows better than we do about the health of our body. This change is exemplified vividly when the doctor becomes the patient.

The category shift from person to patient is depicted by the description of Dontsava, a doctor, who becomes ill. She confers with a colleague as friends talk at a scientific meeting. "Yet having

confessed to being ill was like having confessed to a crime: immediately they had lost the key to equality they once possessed. By her confession she had excluded herself from the noble estate of medical men and transferred herself to the tax-paying, dependent estate of patients". She was crushed and had lost her former bearing.¹⁴⁶

The contrast is further illustrated when we consider the respective physical positions of the two participants in the encounter. It seems that where we are sitting can somehow help to determine our place in the relationship,

Also shown, is the way in which a patient can cross the category gap. Oleg, a patient, helps a nurse analyse some data. He feels that by sitting at the nurse's table he has changed his position, altering his status and so leaving "his other self, the one past help, one of the irremediables", all behind him.¹⁴⁷

As someone who has spent more time with members of the nursing and medical professions not as a "patient" but as a colleague, friend and sometimes manager I can well appreciate the difference that Oleg is expressing, equally I can, to some extent, empathize with the doctor, Dontsava, following my translation from Health Service Manager to patient when I became seriously ill. Being a patient is a role to play and like any role we need to attend to how we play it. This means that on the other side the doctor or nurse is also playing a role and they too must attend to how they go about playing it well. Playing it well will turn out in some way to avoid crushing the person seeking help and to give them back something which they have lost.

Can we be a patient and a person?

It is not uncommon for us to divide ourselves in two when we are ill. We try to carry on as normal living our daily lives in spite of our illness. In the case of trivial and self-limiting illness this can work well, the gap between our will and our ability to carry it out is not large and we cope with our illness until it passes. In the case of serious and chronic illness this is not possible. Anyone who has suffered such illness knows how it disrupts and derails our life. This is because illness is part of our life; it becomes part of who we are. We cannot carry on as usual as our autonomy is progressively reduced by our illness. In the case of serious and chronic illness we have to accept

our illness and learn to live with it, this can make us even more the “patient”. But this cannot be the end of it because while we are being “the patient” we retain the possibility of still being a person, and this understanding importantly characterises our being-a-patient so that as Gadamer says,

It can be argued that anyone who thinks of themselves simply as a ‘case’ cannot receive proper treatment and that doctors cannot help anyone over a serious difficulty, or even a minor affliction when they do no more than simply exercise the routinized skills of their particular discipline. From both perspectives we are partners in a life-world which supports us all.¹⁴⁸

Referring back to the distinction I made in Chapter Three, between the involuntary loss of autonomy that we experience as a result of falling ill and the voluntary surrender of autonomy that we choose when we seek medical assistance, it is incumbent on all of us who provide and receive care to remember that while we are persons we have the possibility of becoming a patient, and once we are patients we retain the possibility of being a person, so that although we must play the part of patient when we seek help from the doctor (or other healthcare professional), they (and we) in turn must bear in mind that we have the possibility of not being a patient and, in fact, the point of our seeking help is to return to being a person. Doctor and patient must play different roles but their aim, the restoration of the personal autonomy of the one seeking help, is shared. In the same way as we are individuals but in a world of entities and Others so we are “patients”, or as Gadamer put it “cases”, while at the same time we are persons with our own unique life-world.

How do we become Patients?

There are a number of factors which contribute to this transformation. First, the doctor really does know better. After all we have only gone to the doctor because we can no longer deal with our illness without their help. Our own resources and those of our family, and perhaps our friends have been exhausted and we seek someone with greater resources. This is immediately manifested as a knowledge gap between us and our doctor and a relationship of unequal power. The doctor is powerful because she has knowledge that we, who are therefore weak, lack. In this situation and

for the best of reasons we assume the subordinate position of supplicant or patient. The danger that this relationship can become dehumanised is present from the start and both sides will have to take care to avoid this. In the end it is “Dialogue and discussion (*which*) serve to humanise the fundamentally unequal relationship that prevails between doctor and patient”¹⁴⁹ From the very beginning we must all be clear as to why we all are in this unequal relationship and retain the readiness to see patients return to the world of persons. Our ability to be the authors of our own lives is fundamental to our being and this must not be lost in the complex process of treatment and the necessary but temporary suspension of this autonomy for the purpose of restoring what illness has taken from us.

Second, there are the biological and normative understandings of illness which predominate in healthcare systems. We present either as machines which are not working properly (biological understanding) or examples which vary from the norm of health (normative understanding). In both cases we are depersonalised by the treatment we receive, treated as machines that have gone wrong rather than persons with a life of our own. Many of us are compliant in this depersonalisation because in the early stages, particularly of serious illness, we do not wish to face the fact that our body is failing. At this stage of illness we do not want to be a patient so we separate ourselves from our illness. It is not ourselves that we take to the doctor for treatment it is our illness. In this way we positively encourage the doctor to treat us in an impersonal way. This strategy is largely effective in the case of trivial and self-limiting illness but soon runs out of road if our illness turns out to be serious or chronic. The problem is that by the time that this happens we have already assumed the object role of patient and, as the disorientation that serious illness brings sets in, we are rendered unable to escape from this role. Those of us who have suffered serious and chronic illness will know that it is a long hard journey back to person from patient. In the case of chronic long term illness, from which we never recover, we have to learn to become people with an illness rather than patients.

Third, there is medical technology, increasingly present in modern healthcare systems and which brings considerable benefits to all of us when we are ill. However the use of medical technology goes a long way to depersonalise both sides of the healthcare encounter, as Gadamer says,

What is important is to recognise the other in their otherness, as opposed, for example to the tendency towards a standardisation promoted by modern technology.¹⁵⁰

Technology can push us in the direction of depersonalisation and a way of forgetting this “otherness”. This is crucial since the recognition of this “otherness” is the recognition of the person being treated as someone like ourselves and when this is forgotten the being of both parties (doctors and patients) is diminished. Patients are attached to machines and seem to partake of the inanimate nature of the machine themselves while operators become part of the machine as it constitutes an extension of themselves, like an extra pair of mechanical hands or eyes. In this machine world personhood can disappear very quickly and it is hard to remain a person when attached by a multitude of leads and tubes to an array of machines that we do not understand. Healthcare professionals who allow machines to take away the otherness of their patients will fail in their ultimate purpose because it is,

Only by means of such recognition can we hope to provide genuine guidance which helps the other find their own independent way. Treatment always involves a certain granting of freedom.¹⁵¹

Fourth, there is the curative impulse. Doctors are trained to cure patients, or more accurately to cure their ills. Those of us who visit doctors accept this too, we go looking for a cure. This jointly held impulse quickly overrides our sense of personal autonomy and whatever sense the doctor may have of us as a person with our own life to lead. It is interesting to consider what happens in the case of hopelessly terminal illness where no cure is possible. In these cases we may find ourselves in a hospice (if we are lucky) and in this environment we find that the emphasis changes away from cure towards making comfortable and respecting the dignity of the

dying individual. The absence of the curative impulse re-focuses care on the person and in this way hospice care becomes notable for its person centered approach. In the case of chronic long term illness the situation is less clear. In effect each presentation to a doctor of a chronically ill patient presents an example of the doctor's failure to cure and this can, in time, so erode the curative impulse that a more person centered relationship between physician and patient can develop. However where there remains the hope, however small, of a cure, the curative impulse in doctor and patient will always preserve this hope and the relationship may never go beyond the mechanistic. This will be further considered later in the discussion of the therapeutic relationship in the context of palliative care.

Fifth, there is the sheer complexity of the process of diagnosis and treatment and the multiplicity of people who we will meet. In healthcare we live in an age of strangers.¹⁵² Particularly in the cases of serious and chronic illness, we are no longer cared for by our own well known, well trusted and often well-loved doctor. We are referred, or passed on, through a bewildering stream of Others who we do not know and who we may never meet again. In the complex world of sub-specialisation which characterises modern healthcare there is little or no chance for us to develop any kind of person-to-person relationship with those who care for us. We all stay in role throughout the process, we as patients and all the rest of them as doctor, nurse, radiographer, surgeon, anaesthetist etc.

All five of these factors make person centered healthcare more difficult and contribute to the surrender of autonomy, dignity and respect that happens all too often when we become patients, but understanding is half the battle towards overcoming the tendency.

The Doctor/Patient Dialectic

It has been said that,

Historically, the practice of medicine has been based on clinical objectivity and detachment from the patient as a person. Writing of the evolution of academic medicine in eighteenth century France, in *The Birth of the Clinic*, Foucault positions the patient as the object of a clinical gaze; the type of gaze with which a botanist examines

plants, or an astrologer the stars. The patient thus represents a passive recipient, rather than an active participant in the clinical encounter.¹⁵³

We would all hope that this is now the expression of an outmoded paternalism, but our experience of healthcare may sometimes betray our hopes in this respect.

I want to argue that the mistake of this kind of paternalism is that it forgets that, ontologically speaking, doctors and their patients form a dialectical unity in which the role of each validates the role of the other and which is fundamentally grounded in a dialogue between the two. I can only be a patient when I submit myself to a doctor and a doctor can only be a doctor when and if they have patients. This is because,

the hermeneutics of medicine is grounded in the meeting between doctor and patient – a meeting in which the two different horizons of medical knowledge and lived illness are brought together in an interpretative dialogue for the purpose of determining why the patient is ill and how he can be treated.¹⁵⁴

Neither role makes any sense without the other. This means that for the doctor to do what I need them to do (to cure my ills) I must enable them to be a doctor by becoming a patient. To become a patient I must surrender (temporarily) some of my autonomy and submit to a relationship of unequal knowledge and power with my doctor. If I am unable or unwilling to do this the doctor cannot assume her own role and treat me. In this circumstance we would meet as autonomous equals which is precisely what I was trying to avoid when I came to the conclusion that my own resources were insufficient for me to cope with my illness. In order for my own needs to be met I must sacrifice some of my own autonomy and become a patient, rather than a person; all this in order to not frustrate my own aims in seeking help. The questions then remain; “How much of my autonomy do I need to sacrifice to make this relationship with my doctor work?”, and “How long must this impairment of my autonomy last in order for me to benefit from treatment?” There are clear decisions to be made about how to be a patient and yet remain a person this is encapsulated in the question “How shall I

live with my illness?” Although when I see the doctor and when I am receiving treatment I am without doubt a patient, it is also true that, for most of the time, even when I am ill, I continue with my life as a person. The only difference is that I am now a person who is ill. As a person I am a phenomenal being and as such I have my being both spatially and temporally, I am no kind of “thing” or fixed essence. This means that not only can I be person and patient without contradiction, but anyone who is involved with me, including the doctors and others who care for me, need to understand me in this way. Anyone who makes me into a patient- object commits a fundamental error as to the nature of my being and thereby fails to relate to me at all. They also deny their own humanity and phenomenological being and turn themselves into mere operatives in a system designed to fix biological machines. Personhood is the reality for those on both sides of the healthcare encounter, forgetting or neglecting this is likely to render the encounter unsatisfactory for both parties, and the only way to remember this reality is through authentic dialogue between those who seek help and those who provide care.¹⁵⁵

When I am unwell I experience this illness as a disruption of my embodied being. It does not make me other than what I am it merely changes the nature of my experience of the world, and it is to this change that the attention of the doctor is drawn and in particular the loss of autonomy that I am experiencing; the gap between what I *will* and what I can *do*. Clearly when I am undergoing treatment or a diagnostic examination, including consultation with a doctor, I will assume the position of a supplicant having temporarily given up some of my autonomy in the hope of receiving assistance from another. However on other occasions, for example when I am discussing treatment options, or simply trying to decide with my doctor whether or not I am fit enough to go home from hospital or to go back to work, I am a person discussing options open to me for my own life. In these cases I warrant the same treatment that would be granted anyone from any Other like myself; that is to be treated as a person. Gadamer sums up what we might call an authentic relationship between doctors and their patients,

In all medical treatment the patient needs to receive guidance, and here the discussion and shared dialogue between doctor and patient plays a decisive role. What we can learn from this conception of the full realization of the doctor-patient relationship as it ought to prevail is that for all these forms of disturbance it is less case of 'taking something away' than of assisting in the process of adaptation and re-entry into the cycle of human, social, professional and family life.¹⁵⁶

In the treatment relationship our shared goal of restoring my autonomy is arrived at through authentic dialogue between two beings who, while their present relationship is unequal, understand themselves as ontologically equivalent. To lose sight of this is to lose sight of the purpose of healthcare.

Wisdom

Before going on to suggest two practical means by which this relationship may be realised I want to return to the notion of empathy and the relation between this and the ancient idea of *phronesis* in order to elucidate from the side of the doctor the way that their relationship with patients can actually work.

As Svenaeus says,

The Greek concept *phronesis* is famously thematized by Aristotle in the *Nicomachean Ethics*, and is usually translated as "practical wisdom", as contrasted to technical skill in arts and crafts (*techne*), the knowledge of science (*episteme*), the theoretical wisdom of philosophy (*sophia*), and intuitive reason (*nous*).¹⁵⁷

This means that,

Phronesis, though not a moral virtue in itself (such as courage or temperance), is accordingly the ability to judge the right end of action in a particular situation and make a wise choice.¹⁵⁸

As that quality which is required in order to do the right thing at the right time *phronesis* becomes a vital attribute of the clinical practitioner and the one thing that a doctor cannot lack. Once we understand the healthcare system as the sum of all the encounters taking place at each moment and in each day, the nature of the dialogue between doctors and those they care for becomes a primary focus for our understanding of what is going on. Svenaeus sums this up when he says,

The clinical encounter can be viewed as a coming-together of the two different attitudes and lifeworlds of doctor and patient – in the language of Gadamer, of their different horizons of understanding – aimed at establishing a mutual understanding, which can benefit the health of the ill party. Doctors (as well as representatives of other healthcare professions) are thus not first and foremost scientists who apply biological knowledge, but rather interpreters – hermeneuts of health and illness. Biological explanations and therapies can only be applied within the dialogical meeting, guided by the clinical understanding attained in service of the patient and his health.¹⁵⁹

This means that “Medical ethics cannot just be “epistemic”; it must also be “phronetic.””¹⁶⁰ We can thus appreciate the familiar and everyday understanding of what is meant by a good doctor as one who does the right thing at the right time for each individual patient, this then further validates and re-affirms the necessity for a person centered approach, because,

The phronimos – the wise man – knows the right and good thing to do in this specific situation; in the case of medicine we would say that he knows the right and good thing to do for this specific patient at this specific time.¹⁶¹

Thus our everyday understanding of what it is to be a good doctor can be seen as grounded in fundamental ontology and the General Medical Council Code of Practice quoted in the introduction of this work now looks like a piece of the philosophy of Heidegger and Gadamer being applied in everyday medical practice. This does not mean that doctors must be phronetic before, or instead of, being epistemic or scientific. It does however mean that if they are not phronetic it will not matter how much scientific knowledge and understanding they have of the ailments of their patients, without phronesis they will be incapable of bringing their knowledge to bear for the benefit of those who seek their help. I will return to this point in a vividly practical context when I consider my own involvement in the East Kent Primary Care Clinical Effectiveness Project in Chapter Six.

Finally in this Chapter I want to consider briefly two practical means through which the benefits of some of this philosophy can be learned and brought into practice, as manifestations of what it means to demonstrate person

centered healthcare. These are, normalising care and mutually informed consent.

Normalising Care Sayers says,

Normal life is characterised, for individuals, by the subjectivity of their experience. They are familiar with being the subject of their daily encounters as well as the subject of their own emotions. To a large extent they become the subjects of their illness. But patients, in some ways, may be treated as objects, dealt with by other people, at worst as inanimate beings, or at best as compliant recipients of care. They may become a part of the stage rather than participating as fellow actors.¹⁶²

The result of becoming “a part of the stage” is dependence and permanent loss of autonomy, whereas the mechanisms of normalising care constitute the process of restoring and maximising autonomy. Fortunately the move towards the increased use of modern communications technology, phone consultations, text messages and the exchange of digital images, which is being made to reduce demands for attendance at healthcare clinics, also promotes a person centered approach. This move is coincidentally normalising care for people who no longer need to attend a hospital or other clinical facility. Instead of the person who is ill (the patient) entering the world of the clinician, the clinician enters the world of the person who is unwell and needs help. In this new situation the person who is ill is not compelled to adopt the supplicant role of the patient and the clinician is forced to recognise the life of their patient beyond the bounds of this role (their life as a person). This serendipitous person centered approach leads to reduced dependence and prepares those for who it is suitable for a greater degree of self-management.

This may sometimes come into conflict with the stringent requirement to ensure the safety of the patient above all things because it is seen as more “risky”, but it is an essential part of restoring patients to personhood. If we are not careful the requirement to ensure patient safety will amount to no more than an unacceptable restriction of the sovereign autonomy of the individual unless the process of healthcare is understood as the

preservation and maximisation of autonomy.¹⁶³ There are times in a person centered system when it is better to respect autonomy and to remember what Mill says about our right to interfere in the lives of others,¹⁶⁴ than it is to ensure safety.

Mutually Informed Consent

The implications of all this for the notion of informed consent could be radical and far reaching, and I propose to do no more than offer an interesting suggestion based on what has gone before in terms of philosophical reasoning. Under current systems consent is obtained from patients either formally or informally. The basis of this consent is that the person about to be treated is given information sufficient for them to understand the consequences of accepting or rejecting treatments. The relationship is one sided and I give or withhold my consent based on what I understand. There is usually very little, if any, of the dialogue which Gadamer sees as the core of the relationship between doctor and patient and this relationship therefore remains decisively unequal. The lack of genuine dialogue can easily lead to a situation in which refusal of consent results in pressure being exerted by the clinician who is both “in the know” and who probably has what they see to be my best interests at heart. Refusal to consent can also lead to doubts about my competence to decide for myself and in extreme cases, and particularly in the cases of minors or those with mental impairment; it can lead to cases being referred to the courts for resolution. This conflict model is discussed and effectively criticised by Yelovich.¹⁶⁵

Clinicians need to appreciate that the person that they are caring for may not make the choices that they would make for themselves, and that this gives them no more warrant to interfere than anyone else. If the notion of informed consent were to be re-cast into a notion of mutually informed consent in which, not only the person receiving the care is able to show that they understand and accept the treatment but, in addition, the person providing the care should be able to similarly show that they understand the individual circumstances of the person they are about to treat, and that they have taken these into account in suggesting a course of treatment.

They would then meet and decide as equals in a genuine hermeneutic dialogue. In the notion of mutually informed consent the relationship is equalized and becomes authentically two sided. There is no presumption that “doctor knows best” and the autonomy of the person receiving care is automatically made paramount. This would, in effect, formalize a person centered approach into every case of consent, and for every person. It would automatically short circuit the relationship of unequal power between doctors and their patients and return the autonomy of the patient to the centre of the healthcare stage where it belongs.

In the next chapter I will move beyond the purely theoretical consideration of person centered healthcare and consider the testimony of what might be called a philosopher-patient, Havi Carel. In addition I will look at what Atul Gawande has to say in his book *Being Mortal* and see if there are lessons to be learned about person centered healthcare from the example of palliative or end of life care.

Chapter Five - Living Well and Dying Well

In this chapter I want to use the very personal reflections of Havi Carel¹⁶⁶ and Atul Gawande¹⁶⁷ in a discussion of living well with illness and of dying well. As an adjunct to this I want to show how the ontology which underpins person centered healthcare is revealed in the practice of end of life or palliative care.¹⁶⁸ These accounts will, not surprisingly, turn out to be typical of what is now called holistic care, an expression more commonly heard in nursing circles than in those inhabited by doctors, which exemplifies ways of working that have really been around for much longer than the terms we now use to describe it. They are the ways of working which include not only empathy but also consideration and sympathy for others, respect for individuality, attending to the psychological and “spiritual” needs of people who are ill, and simply caring. Philosophically these ways of being towards people who are ill represent authentic solicitude in the practice of healthcare. They are perhaps most prominent in palliative care, but I hope to show that they are also central to the delivery of person centered healthcare in all sectors.

Havi Carel – Illness

Havi Carel is a philosopher in Bristol who was diagnosed eleven years ago with lymphangioleiomyomatosis, a progressive disease which, amongst other things causes progressive loss of lung function leading to death. The condition is incurable and rare, occurring only in women and usually between the ages of 30 and 40 years. As a philosopher she turned to what she knew from her own discipline to help her to understand and live with her condition. She is still alive, and new treatments devised since her diagnosis have arrested her loss of lung function for the moment. She is married with a young son.

In her remarkable book *Illness – The Cry of The Flesh* Havi Carel gives us a vivid account of what it is like to be seriously unwell, and above that, a penetrating analysis of the phenomenology of illness.¹⁶⁹ She says, “The first time I couldn’t do something I felt surprise. It came as an insult.”¹⁷⁰ This book itself is constituted in part as a first-hand account of the lived

experience of illness, it is an example of exactly the kind of thinking that Carel is trying to put forward and use in her analysis of the notion of illness. Her very vivid introductory account of falling ill and receiving a diagnosis is written in such a way as to make us understand how she felt, and as a way of showing us that this kind of account has a pivotal part to play in our understanding of not only her own understanding of illness, but of the notion of illness itself. Almost every chapter begins with an anecdote about her own experience of illness. If it works, if it helps us to understand what it is to be unwell, then her method is vindicated. The work is phenomenological and existential in itself, and as such makes a persuasive case for an existential and phenomenological understanding of illness, and by implication, healthcare.

By beginning every chapter but one¹⁷¹ with an anecdote about her own experience of falling ill and becoming increasingly out of tune with her body, she prepares the ground for an explanation of the relationship between herself and her increasingly ill body. In fact this relationship turns out to be less of a separation between her conscious self and her body and more of a demonstration of their essential connectedness. Like Heidegger and Gadamer she rejects Descartes separation of mind and body in favour of Merleau-Ponty's notion of the body subject under which we are understood as embodied consciousness.¹⁷² This is not a reduction to materialism but a rejection of dualism and seeks to understand the combination of the materiality of the body and the mental world which we all experience, and which is the stuff of our ordinary experience of existing. It is by understanding these two as combined right from the start that the problem of how to join them together is avoided. Her approach is firmly rooted in the everyday and is constituted as an interpretation of the everyday experience of being ill and of receiving treatment.

The work of Havi Carel suggests a person centered approach to healthcare, and echoing some of the points made in the previous chapter she says, "There are many terrible things about illness; the lack of empathy hurts most."¹⁷³ This is perhaps the most telling sentence in this book in the

way that it brings to the fore the importance we place on the ways that others behave towards us when we are ill. The same would apply to our own attitudes towards people who are disabled or just getting very old. She uses everyday accounts from her own experience of illness and treatment to illustrate much wider points. Her method is relentlessly phenomenological and existential, focusing wholly on the first-hand experience of the person who is unwell. In doing this she challenges the way in which all of us, not only doctors and nurses, seek to distance ourselves from those who are ill, disabled or ageing. In essence, our response all too often involves reducing the ill person to a status that we would find unacceptable if it were applied to us, as she says elsewhere,

Health professionals often view the body as thematised and objectified, focusing on a particular organ or function in order to understand it as a medical object. But for the patient, the awareness of her body as an object is secondary to her subjective experience of receiving health care.¹⁷⁴

Once this kind of reduction is achieved we are able to treat the person who is ill as simply a set of biological functions which are not working properly, we make them into a medical object. Carel suggests that this way of working in healthcare has developed as a means of protecting those who care for us from the sheer humanity of the suffering of their patients. By withdrawing empathy and treating their patients as objects to be fixed, healthcare professionals are supposed to be better able to get on with their job of using the plethora of technical approaches that are now available to them to make us well. It is probable that advances in medical technology have exacerbated this trend towards the dehumanisation of patients and in increasing the prominence of the biological understanding of illness at the expense of the phenomenological or personal approach. This is a mistake because, in an echo of Gadamer,

Objectivity is seen as an ideal by many health professionals, but when subjected to philosophical analysis, it can be seen that merely relying on an objective stance is a naïve and non-practicable ideal that ought to be replaced with a more nuanced understanding of intersubjectivity.¹⁷⁵

Phenomenology re-humanises healthcare by returning us to the only thing that really matters; the person who is ill and their account of their illness. This approach could also be extended to others affected by the illness including family members and carers. By the ways that she sets out her account of her own illness she demands that those who are caring for her look on her as a person rather than as a mere patient. In terms of the way that we care for the sick this produces a shift from cure towards care, as the first hand lived account of the ill person comes to the fore.

Havi Carel seeks to show how using a phenomenological approach, in which the first hand lived experience of the patients is placed at the heart of our understanding of illness, not only helps us all cope better with the trauma of serious illness but also enables the practitioner to be more (not less) effective in providing care. The more demanding one-to-one relationship that she is suggesting is empathetic because it rejects the objectification of people and their illnesses and insists that, although they may be patients when they are undergoing treatment, ultimately they are persons just like those treating them, and that they all exist as mutually constitutive beings.

In addition she considers the relationship between people who are ill and those who are not and in particular the inability of those who are not ill to imagine what it is like for the other person who is ill. Although the character at the dinner she describes¹⁷⁶ is particularly insensitive in the way he asks about her health and future aspirations he represents an approach which is not entirely exceptional. We all have difficulty in talking to and relating to people who are seriously ill, it reminds us of the frailty of our own healthy lives. Carel recognises that she cannot change the way that everyone thinks and acts and teaches herself to resist the ways that other people try to define her as abnormal. By learning to be rude Havi Carel learns to protect herself from people like this by refusing their definition of her as an illness rather than as a person. While this creates social embarrassment it is better than the alternative. After all, who is perfectly healthy, and who

does not have some characteristic which may be defined by others as “not quite right”? None of us wants to be defined by others in such limited terms.

In the same way that illness changes the physical geography of the world by making it more difficult or impossible to do some things so illness changes the social geography of the ill person. When we are ill we no longer fit into the world of healthy people, and we cannot engage in the same kinds of small talk about health and well-being that people who are well use to acquaint themselves with each other and to pass time together. This means that the person who is ill is steadily disbarred from participation in social encounters and events. In the end it just becomes too much effort for both the ill person and for those who are well, as she says,

Well-being is the invisible context enabling us to pursue possibilities and engage in projects... It is not only physical possibility that suffers in the hands of illness. It is the ways of being and being-with that suffer.¹⁷⁷

When we are well we function without thinking. Most of the normal activities of our lives go on unconsciously and seamlessly. It is when we are ill that we notice the distinction between our biological body and our lived experience. This typically Heideggerian analysis rests on his discussion of the modes of being of equipment in *Being and Time* in which we come to understand the world and our place in it through our engagement with the entities we encounter.¹⁷⁸ We have all experienced some loss of normal body function, usually temporarily, and as we get older more permanently. This experience, of wanting and trying to do something that we are no longer capable of is the experience we have when we are ill, it is a loss of autonomy. We experience a dysfunction between our biological body and our lived experience. This disruption is global because,

Being ill is not just an objective constraint imposed on a biological body part, but a systematic shift in the way the body experiences, reacts and performs tasks as a whole. The change in illness is not local but global, not external but strikes at the heart of subjectivity.¹⁷⁹

It is not simply that our body is a piece of equipment or a set of tools that we are trying to use, and which no longer work, the body is a piece of equipment which cannot really be replaced and moreover, one by which define our very selves. In this way illness is a catastrophic failure of equipment like no other that we can experience; that which we had taken for granted is no longer available. Unlike the slow and steady loss of function that we all experience as we age, illness is a sudden and unwelcome intrusion on the habits that our body has learned and must now unlearn. The lesson for healthcare from Havi Carel's *Illness*, and her subsequent work *Phenomenology of Illness*, is that it is the task of modern healthcare to help us to learn how to adapt as part of its purpose of enhancing and protecting our personal autonomy. *Illness* is a cry for person centered healthcare.

Atul Gawande – Being Mortal

In *Being Mortal* Atul Gawande examines the process of ageing, disability and death across a much wider perspective than does Havi Carel in *Illness*. However the similarity between the two works is unmistakable; both are existential in tone and in composition, both give examples which are moving and personal; both therefore appeal to our common humanity in the hope of evoking a human response to the experiences we must all have at some time in our lives.

Atul Gawande is a surgeon and does not write from the first person experience of illness, nonetheless in his accounts of the illness of others, including his own father; he shows how these experiences propel him towards a person centered approach to healthcare as the only way in which he can help the people he cares for. In his moving and well written book *Being Mortal* he uses real examples to illustrate how different individuals come to terms with their own illness and mortality, in recognition of the fact that suffering illness and dying is something that we all have to do for ourselves. He also considers how they are looked after by the healthcare system both when this is successful in supporting their autonomy and in alleviating their suffering, and when it is not. The cases he sets out chart

the course through denial, hope and eventual reconciliation with the inevitable fact that we are all subject to illness and mortal. Although some of his stories are those of people who have been diagnosed as terminally ill, in many ways these people are no different to all the rest of us. We are all mortal; the only difference is that the people in his book have more definite knowledge about how and when it will end. Gawande gives us stories of the lives of people just like ourselves and charts their illness and declining health in ways that we can recognize in our own lives. He draws conclusions about how we might best care for people who are ill and how we might conduct ourselves along the uncertain course of our own lives. The story of Felix and Bella¹⁸⁰ in which Felix takes over the care of his wife as her health declines, while at the same time coping with his own failing health, is familiar in our society where people live longer but not necessarily healthy lives. It seems that we can all learn a lesson about what really matters. As he says, “we all seek a cause beyond ourselves”¹⁸¹ and in this cause, whatever it might, be we each find the meaning which makes life worth living. Conversely the removal of “a cause” can make life not worth living. When we really understand ourselves as finite beings we get a perspective on our lives and the things that matter so that,

People with serious illnesses have priorities besides simply prolonging their lives... Our system of technological medical care has utterly failed to meet these needs.¹⁸²

In this way we are all not unlike Socrates sitting in the cell waiting for the ship to return.¹⁸³ He does not know exactly when the ship will return and when his execution will proceed, he just knows that it will, and he makes his choices about how to live according to the lessons he has learned in his long life about what makes life worth living. In Socrates case it is his life in Athens and his unceasing quest for knowledge and truth which are more important to him, more important even than his family. Our own choices may be different but we all have to make them for ourselves, to be the authors of our own lives. When we do make our choices we would like others to take notice.

As a stark reminder to all of us, Atul Gawande sets out cases in which people who are living independently are suddenly, through illness or accident, left needing help to continue with their lives.¹⁸⁴ He is able to show through these case studies that a response (nursing home care) which takes away what remains of their independence, and which removes them from their own world, reduces people to objects to be cared for. By making permanent patients of people who have become infirm or disabled we risk making their lives not worth living, by taking them away from all of the little things that make it worth living. Sometimes, like Socrates, it may be better to choose a bit less safety and a bit more freedom. It is interesting that the practice of sending infirm or disabled people into the exile of nursing home care is most often confined to the elderly who, it seems, we feel have less life left. Ironically this somehow makes it alright to disregard the quality of their lives in favour of keeping them safe until they die, as Gawande says it is strange that,

Many of the things we want for those we care for are things that we would adamantly oppose for ourselves because they would infringe upon our sense of self.¹⁸⁵

We should pay as much attention to the quality of the lives of old people who are infirm as we do to the quality of the lives of young people who become disabled.

His example of the Chase Memorial Nursing Home¹⁸⁶ and the work done there by Bill Thomas illustrates how having something that matters in our lives makes a difference not only to the quality of our lives but even to how long we actually live. By bringing life into the lifeless nursing home (in the forms of dogs, cats, birds, plants and children) Thomas revitalized the institution and as Gawande says,

The most important finding of Thomas's experiment wasn't that having a reason to live could reduce death rates for the disabled elderly. The most important finding was that it was possible to provide them with reasons to live, period.¹⁸⁷

There are lessons to be learned from the examples that Gawande sets out and these are the lessons that he learns for himself from his own experience of the illness and dying of others. As a surgeon he admits that he began with a very simple understanding of healthcare. He was trained to fix people who went wrong; he became an expert in the technical and almost mechanical aspects of medicine. As his career progressed the various professional and personal experiences that he had of illness and dying made him re-consider this simple perspective and to try to gain a deeper understanding not only of what he could do for people who are ill, but what these people actually want him to do for them. We see this movement when he says,

Scientific advances have turned the process of ageing and dying into medical experiences, matters to be arranged by healthcare professionals.¹⁸⁸

He is critical of the process that has been created because,

Our reluctance to honestly examine the experience of ageing and dying has increased the harm we inflict on people and denied them the basic comforts they most need. Lacking a coherent view of how people might live successfully all the way to their very end we have allowed our fates to be controlled by the imperatives of medicine, technology and strangers.¹⁸⁹

Whereas it is probably more true to say that, “as people’s capacities wane, whether through age or ill health, making their lives better often requires curbing our purely medical imperatives.”¹⁹⁰ Like Socrates some of us may choose a shorter but more meaningful life.

The Problem of Hubris

The problem of hubris is one that the ancient Athenians would have recognized and one which Gawande discusses.¹⁹¹ The remarkable progress in medical science that we have experienced in our own lifetime has given some of us the impression, erroneous as it turns out, that all illness is curable. In effect we lack the wisdom to accept what we do not know and consider ourselves to be much more clever than we really are. It is in the cases of serious and terminal illness, and simply in the acknowledgement of our own ageing and loss of capacity, that our hubris

is exposed, and this is when we have to come to terms with the fact that we can no longer pretend that we are immortal. It is at this point that what we want from our healthcare system begins to change. Collectively we face the problem of how to create a healthcare system which helps people to achieve their goals within the sphere of their own capacities, I think that Atul Gawande, like Havi Carel, believes that the most appropriate response to this question is to re-establish the personal through a phenomenological understanding of ourselves as finite (mortal).

Gawande suggests that simple things, like asking people who are ill how they want to live their lives, including how they want their condition to be managed, and then offering the kind of care which meets what they want, is the way to do this in practice. This is a process which sounds simple and obvious but is often forgotten and absent in modern technological healthcare. It is sad, from the examples he gives of people who can no longer live independently, and people who are terminally ill, that the imperatives of person centered care only seem to come to the fore when the option of restoring us to our former lives is removed. In this extreme circumstance healthcare has no option but to find a way to manage, as opposed to cure, our declining health. To do this we have to attend to the person and to factors which appear at first to go beyond what we understand by healthcare; to explore what kind of lives people want given the restrictions of their illness or loss of capacity. Gawande reminds us of the story of Ivan Ilyich,¹⁹² in which the relatives and friends of the dying man fail to recognize his simple human needs and it is only his servant, Gerasim, who can provide him with what he wants. The pity is that we still have not learned what Gerasim seems to know by instinct,

This simple but profound service – to grasp a failing mans need for everyday comforts, for companionship, for help achieving his modest aims – is the thing that is still so devastatingly lacking more than a century later.¹⁹³

Gerasim appears to be an early practitioner of person centered healthcare, he understands what is happening to his master and knows what to do for

the best, while others either look away or scratch their heads, with no real idea of what to do next as the man dies before them.

In the Epilogue to his book Gawande sets out the lessons that he has learned and which he thinks are central to the creation of a better healthcare system, he says,

We think our job is to ensure health and survival. But really it is larger than that. It is to enable well-being. And wellbeing is about the reasons one wishes to be alive. Those reasons matter no just at the end of life, or when debility comes along but all along the way.¹⁹⁴

We are all mortal, and we all need looking after at some time or other, so perhaps what Atul Gawande is saying about the care of those who are chronically and terminally ill should apply to all of us, as we get ill and lose the capacity to do the things we used to do, even when we have the prospect of recovery from illness. He talks about how we face the great unfixables of mortality and death. While science has made tremendous advances and we can all, in western society, live longer more comfortable lives, the end of our lives has become a medical event. In this way it has been reduced to the mechanical kind of event which increasingly disregards the personal (or phenomenological) dimension. In common with Havi Carel Atul Gawande wants to re-emphasize the personal and recover from medical science the way we suffer illness and die, and to restore it to an appropriate place in the course of our living. In short he is saying that we should take more care to make sure that people have lives worth living as well as longer lives.

At the end of *Being Mortal* Atul Gawande explicitly recognizes that the person centered ways of thinking about healthcare that he is putting forward are already present in the practice of palliative care.¹⁹⁵ In the final section of this chapter I will look briefly at the principles and some of the practice of palliative care and try to understand what it is about palliative care that makes it person centered.

Palliative Care

The United Kingdom General Medical Council defines palliative care as,

The holistic care of patients with advanced, progressive, incurable illness, focused on the management of a patient's pain and other distressing symptoms and the provision of psychological, social and spiritual support to patients and their family. Palliative care is not dependent on diagnosis or prognosis, and can be provided at any stage of a patient's illness, not only in the last few days of life. *The objective is to support patients to live as well as possible until they die and to die with dignity.* ¹⁹⁶

It suggests that doctors should,

give patients who are approaching the end of their life the same quality of care as all other patients. You must treat patients and those close to them with dignity, respect and compassion, especially when they are facing difficult situations and decisions about care. You must respect their privacy and right to confidentiality¹⁹⁷

The imperatives expressed in this guidance already beg the question as to why doctors should not behave like this towards all of their patients all of the time.

There are of course clear definitions as to what constitutes "approaching the end of their life, (usually a prognosis of twelve months or less), but a more flexible interpretation would see an extension of the imperatives expressed in this guidance to many more of us as we age and become infirm. As Heidegger says, "Death is a way to be which Dasein takes over as soon as it is. As soon as man comes to life he is old enough to die."¹⁹⁸ Heidegger is here expressing our inescapable futurity, the fact that we all exists as temporal and finite beings. To put it crudely, we might say that all of us are suffering from the terminal condition of life and we should expect, throughout our lives, the same kind of person centered care which is at the moment reserved for those close to death.

It is notable that the first of six ambitions given in the *Ambitions for Palliative and End of Life Care* is that, "Each Person is seen as an individual" ¹⁹⁹ and the same document says that,

Everybody approaching the end of their life should be offered the chance to create a personalised care plan. Opportunities for informed discussion and planning should be universal. Such conversations must be ongoing with options regularly reviewed.²⁰⁰

Again, perhaps we should expect to be treated as individuals whenever we need healthcare.

Overall, all of these entirely laudable aims and ambitions are unremarkable in documents setting out principles and actions for the care of people who know that they have not very long to live. They are all essentially first and foremost person centered aims and ambitions. People who are in this position are not to be treated as medical objects but as persons to be regarded as deserving considerations of dignity and choice. There is a clear resonance here with Heidegger's notion of authentic solicitude which I set out in Chapter Four. However, and in reality, as we pass from the hands of those who seek to cure our illness into those who offer palliative care, it is all too obvious that a change occurs in the ways that we are regarded, albeit a welcome change. While we are ill, but have hope of recovery, we are too often treated as medical objects to be "cured". Once curative medicine exhausts the options, those who practice it have nowhere to go. This is traditionally the point of referral to palliative or end-of-life care. From this point we can now no longer be treated as the medical objects of curative medicine and must be treated as persons, simply because there is nothing else. It is ironic that we may have to wait until our life is nearly over until those who are caring for us begin to treat us like the persons that we are and that we have already been for all of our lives. The step from an inauthentic relationship between doctors and those they care for, to an authentic way of Being-with-Others comes too late, a regret which is sometimes expressed by those who experience palliative care and wish that they had been referred sooner.

Being-towards-death

The medical profession must not take all of the blame for this; the curative impulse is strong in all of us. We go to the doctor seeking a cure for our ills and, at least initially, we base our decisions about the advice that we

receive on the prospect of more, not less, life. We all live our everyday lives inauthentically and specifically with an inauthentic relationship towards our own demise. In short, we want a cure as much as the doctor. Heidegger says,

As falling, everyday Being-towards-death is a constant *fleeing in the face of death*. Being-towards-the-end has the mode of evasion in the face of it - giving new explanations for it, understanding it inauthentically, and concealing it.²⁰¹

Death is turned into something we must fear and, “The “they” does not permit us the courage for anxiety in the face of death.”²⁰² It happens not yet and not to me. We see this realized in practice as Atul Gawande cites cases²⁰³ in which patients continue with increasingly unpleasant, and decreasingly effective, treatments, rather than shift their focus away from the impossible future and towards the present. Even at this stage we should not forget that medical objectification is a mutual collusion engaged in by both doctors and all of us when we are unwell. In the case of minor, self-limiting and curable illness we can get away with this inauthentic attitude towards finitude and relation towards others, at the small cost of the temporary loss of autonomy which being a patient entails. But when we are confronted with terminal or long term chronic illness we are brought sharply face-to-face with our own finitude, and we begin to behave as persons rather than as patients, and demand to be treated as such. In turn the healthcare system at last recognizes us as persons and begins to behave accordingly.

It is natural that the care of the terminally ill involves a change in priorities in relation to the patient, because treatment designed to cure becomes increasingly irrelevant as the disease progresses. It is really no surprise that the ideas that drive practitioners in palliative care are those of respect for others, the primacy of the individual, the autonomy of the person who is unwell, the satisfaction of immediate desires and needs, and similar person focused notions. Things like friendship, company and immediate physical comfort become more and more important as the curative impulse

wanes. The relationship between the professional and the person who is ill is changed as both of their expectations as to the possible outcomes are changed. This new relationship not only more closely reflects their deeper ontological relationships (Being-with-Others and Being-towards-death) it is perhaps the kind of relationship we would expect to see characterize all contact between those who are ill and those who care for them. Palliative care is perhaps the most honest of all parts of medicine. By working so closely with the fact of death it makes no attempt to deny the inevitability of death and therefore engenders an authentic relationship with death and finitude.

It appears that the kind of approach that I have been suggesting as person centered, throughout this work, is realized in the practice of palliative care. As Atul Gawande says, even if this is not cause for celebration, it is certainly cause for encouragement.²⁰⁴ By making illness, and eventually death itself, a medical event we make medical objects of everyone who is ill and dying. The visible difference between curative medicine and palliative care is the possibility of complete cure and the return to our lives as they were before. In the bleakest possible terms we might say that the change to palliative care is the removal of hope, but in more positive, realistic and authentic terms we can say that it is the beginning of the understanding of ourselves as finite beings which liberates us from the inauthentic interpretations of "*the they*". Death is as Heidegger so decisively puts it, "*that possibility which is ones ownmost, which is non-relational and which is not to be outstripped.*"²⁰⁵ Death is thus quite the most personal event in our lives as the thing which we must do alone, cannot transfer to another, and which cannot be avoided. In the practice of palliative care this is recognized and acted on. Good palliative care is therefore probably the most authentic kind of healthcare because it is the most person centered kind of healthcare.

Conclusion

Havi Carel, Atul Gawande, and even a brief look at the principles of palliative care bring to our attention the possibility of realizing a person centered approach in healthcare practice. In the final chapter of this work

I will look briefly at two projects, in which I have had personal involvement, as a manager and as a patient, which I think offer some hope that modern healthcare can become person centered. I hope by then that it will be clear how the lessons that we can learn from these examples, and from the philosophical approach that I have been using, can be applied in many other areas of healthcare.

Chapter Six - Conclusion

In this concluding chapter I will refer briefly to two examples of a person centered approach in action; one from my own experience of coping with serious illness, and the other of implementing a large clinical effectiveness programme in United Kingdom General Practice. Although this is primarily a work of philosophy and has been therefore mainly and necessarily concerned with philosophical theory, my endeavour in this section will be show how the philosophical position which I have shown to underlie person centered healthcare, can be effective in the practice of commissioning and providing healthcare, and conversely how the philosophical ground that I have revealed is manifest in healthcare practice.

MyStoma

Eight years ago I underwent major surgery for the removal of my inflamed colon. I had suffered from ulcerative colitis for a number of years and the time had come to make a change. I have now had my ileostomy for eight years and my life is much better than it was before. As a result of my surgery I met other people who have a stoma and, because of my experience of working in the Health Service, I became their local spokesman. To cut a long story very short, through my involvement with the other ostomists (as we call ourselves) and the willing partnership with our local stoma care team, we have developed a new way for all of us who have a stoma to be at the centre of the development and improvement of the services we receive. This is now called the *MyStoma* project and I think it represents a successful working example of person centered healthcare.

MyStoma is run jointly by East Kent Stoma Support Groups and the Stoma Care Service of the East Kent Hospitals Trust, with support from our commercial partners (Dansac, Fittleworth Medical and Salts Healthcare).²⁰⁶ The project gives a voice to people who have a stoma and ensures that the care that they receive reflects their own needs as expressed by the ostomists themselves. The aim of *MyStoma* is to change the way that people who have a stoma are involved in the development of the services provided to them and to put their needs and expectations at

the heart of all decisions made about stoma care services. We are developing a new model of engagement which makes the experience of those who have stoma the starting point for service improvements.

Everything we do in *MyStoma* is based on the phenomenologist starting point that; only the person with a stoma knows what it is really like to live like this, the lived experience of each person with a stoma is unique. With this in mind we began by simply asking individual ostomists what they wanted from the Stoma Care Service. To focus on the experience of ostomists we found that it is necessary to ask only two kinds of question: Questions which ostomists can answer, thus avoiding questions involving the complexities of *how* services are provided, and questions which *only* Ostomists can answer, because information about their experiences is not available from any other source. In practical terms this means questions like:

What do you expect from the Stoma Care service?
What was good about the service when you used it?
What needs to be improved?

By talking to people who have a stoma and listening to the stories they have to tell we have created a simple and clear Ostomist Agenda. The Agenda is at the heart of *MyStoma*. It is held by the ostomists and only someone with a stoma can add items to the agenda. Our Agenda now forms the basis for all service development plans for providers and commissioners of stoma care in East Kent. This means that for the first time changes in the way that services are provided will be related to the things that people who have a stoma have said they want. This is the significant change that *MyStoma* is bringing to stoma care in East Kent.

The Agenda acts as a clear and simple reminder to stoma care professionals that ostomists are at the centre of everything they do. It ensures that the voice of the ostomist is never lost even when we are not present in the discussions about how care is provided. By providing a clear statement of the expectations of people who have a stoma the Agenda acts

as a proxy for the ostomist voice and enables providers and commissioners not only to tailor service developments to these expectations, but to clearly show those they care for that they are responding to their needs and expectations.

The Ostomist Agenda is under constant review; it is never finished and as we talk to more people with a stoma, items are changed and added. Those who provide the service are committed to delivering the items on the Agenda and report regularly to the Stoma Support Groups about the progress they have made in delivering our agenda. Significant improvements have been made, in particular the establishment of post-discharge and out-of-hours telephone support, and community based stoma clinics, all of which are areas of service which everyone with a stoma values highly, and which will help them to become more independent and reduce their need to use hospital based services.

MyStoma works because we begin and end with the experience of Ostomists. This has resulted in an approach which recognises clear roles for everyone involved, including the Ostomists, and puts their experience at the centre of everything we do. *MyStoma* ensures that Ostomist voices are heard and injected into the process of service change and development and that this is a continuing process. Beginning with a Ostomist Agenda based on the stories of real experiences of having a stoma, all healthcare professionals involved in stoma care not only have a clear statement of what the people they care for think is important, but *MyStoma* gives them a thread of accountability along which they can return to their patients to show how much of the Ostomists Agenda is being delivered, as a measure of their own person centered practice. By focusing on the individual experience of people who have a stoma *MyStoma* encourages Ostomists to come to terms with their stoma and to become more independent, thus reducing the demands on the service at the same time as producing higher levels of satisfaction with the Stoma Care Service. *MyStoma* is person centered healthcare in action.

The process of implementing *MyStoma* has not been easy (we have no funding and no support from our local commissioners) but, in terms of the underlying philosophy, the conception of *MyStoma* is simple. It is an unremittingly person centered project which proceeds from the lived experience of people who have a stoma, to the development of services to meet these expectations and needs, and then back to the experience of those who are on the receiving end. The process is therefore phenomenological, existential and hermeneutic. Everyday experience is used to ground the ideas for service development and these ideas are returned to the everyday in the form of new and improved services, which then produce new experiences which in turn generate more thinking about service provision. Or to put it another way, the everyday experience of ostomists is interpreted and these interpretations lead to service developments which are then returned to the everyday lives of ostomists. The first hand lived experience of the ostomists is at all times central to the process and no-one who is involved in the commissioning or provision of stoma care in East Kent can ever forget or neglect this, in this way the process remains person centered. The service cannot be static, it must ever respond to the changing needs and expectation of the ostomists.

It is becoming clear that both the philosophy underlying *MyStoma* and the methodology that we have used could be extended into other areas of care. If we can have *MyStoma* then we could have *MyDiabetes*, *MyArthritis*, *MyColitis* or *My* anything else and, while this would go well beyond the scope of this thesis, it suggests that the philosophy of person centered healthcare could have a significant practical impact on the way that many people are cared for when they are ill.

East Kent Primary Care Clinical Effectiveness^{207,208,209}

My second example concerns a project I managed some years ago while I was still working as a National Health Service manager in East Kent. This ambitious project was an early attempt to introduce evidence based care into General Medical Practice. Standards were agreed in thirteen disease areas against evidence based clinical criteria and East Kent GPs were offered the opportunity to accept funding on the basis that they would meet

the agreed standards. This voluntary project was devised as a vehicle to take the evidence drawn from clinical trials and to implement it in a real life population. In the end the project was so successful that, within four years, almost all GPs in East Kent had joined and the project was used as the model for the UK General Practice Quality and Outcomes Framework, which now forms part of every GP contract in the United Kingdom.

It may appear that this kind of evidence based approach is about as far from person centered care that we could get, but our experience in implementing and monitoring the project revealed a very strong person centered approach from the GPs, driven by their own professional pride and their determination to meet the agreed standards. In order to transfer the evidence from the strictly controlled conditions of the clinical trial to the complex reality of their real life patients our GPs found that they needed to employ a person centered approach, and to treat each patient as an individual with unique needs and responses. To do otherwise, to treat them under a purely biological or normative understanding of illness, was not effective in gaining their compliance with the treatments, which the GPs needed in order to for them to meet the standards and to quality for payment. This suggests that to be effective in delivering improved outcomes an evidence based approach needs to be person centered.

GPs were allowed to choose their own means to achieve the standards in individual patients. This was not a project based on guidelines and the prescription of the process of delivering healthcare. Criteria were chosen based on evidence and standards agreed with representatives of the participants, but it was up to individual GPs to determine how they went about meeting the standards in their own practice populations. They were also allowed to remove from the audit cohort any patient meeting agreed terms for exceptions. These included patients who refused the necessary interventions (informed dissent), those who experienced adverse reactions to the drug treatments recommended for their condition and those with a supervening condition (terminal illness and short life expectancy). In this way the GPs were supported in making person centered judgments in

respect of each of their patients and allowed to retain their own professional discretion and autonomy in the treatment of their patients. Both of these turned out to be significant factors contributing to the success of the project, so that although the criteria were evidence based, their application to individual patients had to be person centered. We are reminded here of the case of the asthmatic ballet dancer.²¹⁰ People have many reasons for consulting the doctor and many reasons for taking notice of the advice that they receive, the success of the Primary Care Clinical Effectiveness Project in East Kent showed that to bring the benefits of evidence into practice doctors need the agreement, or at least the acquiescence, of their patients and that this is best obtained by using a person centered approach.

It is important to note that neither the GPs involved in this project nor those involved in its implementation were specifically promoting a person centered approach. Our aim was to bring clinical evidence into everyday practice. The person centered approach developed through practical necessity (the interpretation of everyday practice) in order to enable everyone involved in the project to bring the benefits of evidence into the lives of large numbers of people. This project was not driven out of a desire to put into practice a piece of academic philosophy but out of the desire of clinical professionals and Health Service Managers to do the best they could for people who were unwell, and to do this they developed a person centered approach. The value of a person centered approach was a lesson learned from practice, the philosophy which became manifest in the everyday work of the GPs came later as a lesson for future successful work in this area. It was only in analyzing the reasons for the success of the project that the importance of the underlying philosophy became apparent.^{211,212} We were operating in a phenomenological, existential and hermeneutic way, not because this was our pre-determined method but because this was the way that worked for everyone involved, including the recipients of care. Philosophy became manifest through everyday practice.

By allowing the GPs to retain their autonomy and to act on their professional discretion, by modifying the application of standards based on

feedback from the GPs, by treating them as persons, the project allowed, and even encouraged, the GPs to treat their patients as persons in the ways that they applied the evidence. This validation of a person centered approach through practical necessity demonstrates how philosophy and practice are bound together each driving the other in a continuous process of development. The East Kent Primary Care Clinical Effectiveness project was certainly, “a complex clinical, human and moral endeavour”²¹³, and in addition it was a great success.

Why Person Centered Healthcare?

In this work I have set out the ontology of person centered healthcare and shown how this is manifested in the practice of healthcare. I began with quotes from the United Kingdom Medical and Nursing codes of practice and I believe that the arguments that I have brought forward in this work show how these fine intentions, from two highly respected professional bodies, can be seen to be based on sound philosophical thinking. By establishing a philosophical basis for a person centered approach to healthcare for those involved in the provision and commissioning of care, I have provided an intellectually consistent method with which they can achieve their aim of giving help to those who need it and in the ways that they would like to have it given.

I began by setting out a phenomenological existential hermeneutic approach based on the work of Heidegger and Gadamer and showed how this approach is particularly suited to an understanding of illness and healthcare. Using Heidegger’s work on the “problem of other minds” I set out the ontological and mutually dependent relationship between people who are ill and those who care for them, a relationship grounded in their mutual personhood. I then argued that the purpose of healthcare is the restoration, preservation or maximisation of personal autonomy and that any interpretation of healthcare which did not include this would be self-defeating of the end of healthcare. While accepting that the notion of personal autonomy is not simple and that there are many varied and complex scenarios that occur every day in every healthcare system, all of

them, however complex and varied, conform in essence to this basic analysis of loss and attempted restoration of autonomy.

In Chapter Four I discussed specifically the central relationship between clinicians and those they care for (doctors and patients) using a dialectical model and Heidegger's notion of solicitude. I was then able to set out the barriers to person centered healthcare and to begin to suggest how these can be overcome.

In Chapter Five I moved onto more practical aspects of person centered healthcare using the work of Havi Carel and Atul Gawande to show how the philosophical approach that I have set out can be seen and used in what we see as the successful practice of healthcare, and which is notable by its absence in what we see as unsatisfactory practice. In the examples provided by Gawande and Carel we see a person centered approach resulting in more autonomy for those who are ill, even in cases of terminal illness, thus demonstrating that a person centered approach best serves the end of healthcare. In the work of Havi Carel the philosophical ground is revealed alongside the account of her own first-hand experience, while in Atul Gawande's work this ground gradually becomes manifest as he sets out the cases in his book. Both use phenomenological method to reveal underlying ontology in precisely the way that Heidegger recommends, and both produce compelling cases for person centered healthcare. The example of palliative care illustrates that there is at least one extant model of person centered care from which we can learn lessons for the establishment of person centered care in other areas of healthcare, as part of the process of restoring and maximising the autonomy of everyone who is in receipt of care.

Finally, in this concluding chapter I have provided two examples from my own experience which both illustrate the benefits of a person centered approach for everyone involved in healthcare and show how the philosophical ground is revealed in effective practice.

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