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***"All in the same boat. The nightmare has gone and you're with other like-minded people"<sup>1</sup>***

**Report to the Parkinson's Disease Society (UK):  
Psycho-social impact of participation in a holistic  
therapy programme for people with Parkinson's  
Disease, volunteer therapists and family members**



**Professor Carolyn Kagan and Dr Diane Loggenberg, Research  
Institute for Health and Social Change, Manchester Metropolitan  
University  
April 2007**

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<sup>1</sup> Quote taken from an interview with Joseph (retired rugby player with Parkinson's),

<sup>2</sup> Photo taken in the hotel bar on Friday November 3<sup>rd</sup> 2006, following the Gala Dinner (attended by the Town Mayor): Two people with Parkinson's enjoy watching 'Showtime' with their accompanying partners.

## Acknowledgements

The researchers involved with this project would like to acknowledge the financial support, from the Parkinson's disease Society (UK) (PDS), that enabled this investigation to be carried out. Furthermore, without the participation of such people as the PDS employment specialist, PDS affiliated physiotherapists, and indeed the Research Officers based at Head Office in London, this evaluation of the Holistic Therapy Programme would have been considerably impoverished. From outside the domain of the PDS, the first person to be thanked must be Mr. Alan Pulford who, despite increasing health challenges, ensured high visibility for the Blackpool Holistic Therapy Programme throughout the entire year of 2006, right up until the funding for this evaluation was assured and ultimately, in place. He felt strongly that the tradition of the Blackpool Week could not be lost without it first being fully empirically appraised. Credit must go too, to the specialist therapists (physiotherapists, nurses etc) who had so few free moments of their own that week, yet still managed to find small pockets of time to talk to us, thus supplying some much-needed, much-appreciated authoritative input. Those to whom the greatest debt of gratitude must go though, are the people with Parkinson's (PwP) who made themselves available for interview, and also their partners, who made additional, invaluable contributions to the overall evaluation. It is our belief that the insights and inputs they provided, enable a comprehensive assessment of the value of the week long programme.

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# **1. Executive Summary**

**A psychosocial evaluation of an annual Holistic Therapies Programme, consisting of ten different activities, for people with Parkinson's Disease was undertaken with the following aims:**

- 1. To gain information participants' reported positive and negative experiences of different activities on offer during the holistic therapy week, in terms of their wellbeing (satisfaction and pleasure as well as personal development and growth);**
- 2. To assess the extent to which gains in terms of quality of life, or wellbeing through participating in the in the week last over time;**
- 3. To provide information that will lead to the enhancement of future holistic therapy weeks as well as the viability of holistic therapy programmes for use elsewhere.**

**Different methods were used to collect information. These included Quality of Life (as measured by the PDQ39 scale) measurements prior to and two months following the week and interviews and discussions with 30 people with Parkinson's Disease, 18 carers or family members and 12 volunteer therapists.**

**The quality of Life questionnaire failed to identify any changes in the quality of life domains of mobility; activities of daily living; emotional wellbeing; stigma social support; cognition; communication ; and bodily discomfort over time. However, other sources of information clearly identified positive impact on social, emotional, physical, leisure, and personal wellbeing. People with Parkinson's Disease, their carers and volunteer therapists gained in terms of both satisfaction and personal challenge and development during the course of the week. They also experienced greater social inclusion during the course of the programme.**

## **2. Background:**

### **2.1: Quality Requirements for People with Parkinson's**

In March of 2005, the Dept of Health published 'Quality Requirements' (QR), a paper that aimed to '*transform the way health and social care services support people with long-term neurological conditions*' (National Service Framework (NSF), p15). This potentially transformative document is of particular interest to any researchers working in the field of Parkinson's disease (PD) in the UK because, by detailing the requirements of 15 separate QRs (covering issues as diverse as: diagnosis, service delivery, treatment recommendations and rehabilitation) there are now standard measures against which, all those involved with PD care, can be assessed. In the context of current policy recommendations for the nation, these QRs are both necessary and judicious.

Recognising, like the Dept of Health has, that people with long-term neurological conditions need '*an holistic, integrated interdisciplinary approach to care*' (ibid, p15), the PDS mission statement now reflects general holistic concerns about the wellbeing of people with Parkinson's and not just medical matters. One of its major objectives is: '*to help people with Parkinson's and their cares and families with the problems arising from Parkinson's*' (PD Society Website, 2006). The Dept of Health QRs require that approaches to care involve more than just improved survival rates, now recognising that a long life is not necessarily a good life, so paragraph 5 relating to QR2, requires that overall, '*the person's quality of life*' is improved (NSF, 2005, p15). This may be achieved by '*providing well-coordinated, long-term support, (as it) is at least as important to QoL as prompt diagnosis*' (ibid, p16). Such long-

term support may be difficult to achieve in the light of the psycho-social exclusion barriers which are known to exist for anyone with PD, unless future public services are planned in consultation with those who will benefit from them (Kagan & Lewis, 1999).

## **2.2: Quality of Life and Wellbeing**

The term 'quality of life' has gained strong academic, scientific and popular currency. It is now generally accepted that quality of life is as important as survival. It is, however, difficult to assess and is a term that has been described as poorly defined but widely used.

Academia has also embraced the concept of QoL. However, despite general acceptance of a QoL model, there is still little consensus regarding *who* should provide the definition of what gives a life quality and against what criteria QoL should be assessed. Prutkin and Feinstein (2002), reported on research he undertook to examine the history of the term QoL and how it was generally used. He found all of the following components of QoL in the studies he reviewed: *'general health status, functional capacity, emotional function, level of wellbeing, life satisfaction, happiness, intellectual level, pain, nausea and vomiting, level of symptoms, fatigue, sexual functioning, social activity, memory level, financial status, and job status'* (p3).

Together with seven other colleagues, Bowling et al. (2003) carried out interviews with 999 British people, in a concerted attempt to definitively unpack the correlates of life quality. Together they discovered that *'the concept and measurement of quality of life are dependent largely on expert rather than lay views of the important constituents'* (p270), and that QoL was an amorphous concept reflecting both *'macro societal and socio-demographic influences and also micro concerns such as individuals' experiences,*



*circumstances, health, social wellbeing, values, perceptions and psychology ... a collection of interacting and subjective dimensions'* (Bowling, Gabriel, Dykes, Dowding, Evans, Fleissig, Banister & Sutton, 2003: 271).

More recently the term 'wellbeing' has received attention, and has become a cornerstone of public policy, embracing not replacing quality of life. Shah and Peck (2005:2/3), in the context of mapping out the terrain of wellbeing, remind us that: *'...there is much more to life than satisfaction: people also want to be leading rich and fulfilling lives - developing their capabilities and fulfilling their potential... For people to lead truly flourishing lives they need to feel they are personally satisfied and developing'*.

Shah and Peck thus propose two dimensions of personal wellbeing:

- *Peoples' satisfaction with their lives, which is generally measured by indicators which capture satisfaction, pleasure and enjoyment;*
- *Peoples' personal development, which includes being engaged in life, curiosity, 'flow', personal development and growth, autonomy, fulfilling potential, having a purpose in life and feeling that life has meaning.*

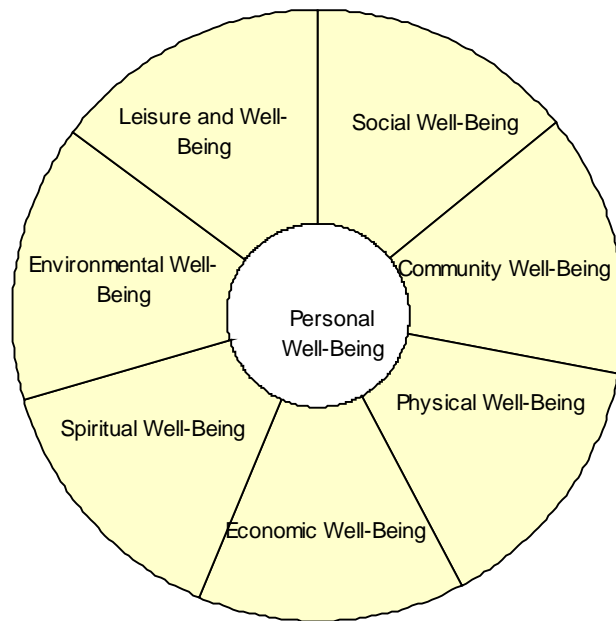
For Shah and Peck, then, eudaimonic wellbeing (personal development and fulfilment) is as important as hedonic wellbeing (satisfaction and happiness).

Kagan and Kilroy (2007) suggest that both the hedonic and eudaimonic wellbeing of people with long term conditions are inseparable from: their economic position; the environmental conditions in which they live; the impact of their condition; and also from the human services that exist to

**assist them. Woolrych, Sixsmith and Kagan (2007) summarise different life domains in which wellbeing can be experienced and expressed. These facets of wellbeing include leisure, social, community, physical, economic, spiritual and environmental wellbeing (see Figure 2.1).**

**Both the concepts of quality of life and of wellbeing for people with physical impairments and with long term, sometimes deteriorating conditions, take on a different hue.**

**Figure 2.1: Conceptual Model of Wellbeing (from Woolrych, et al, 2007)**



**According to Williams (1996), people who are physically compromised need to be able to *'take positive actions to realign the relationship between body, self and society'* (p32). Using alternative therapies might be considered to be one such positive action, and Rajendran & Thompson (2001) reported that 40% of PwP used at least one form of alternative therapy to alleviate problems with their disorder. Brandabur (2004:21) later noted that alternative therapies might give indirect benefits: *'the effects of some therapies may include factors that are difficult to measure such as lessening of stress or an increased sense of wellbeing'*.**

### **2.3: Psycho-Social Impoverishment and Parkinson's**

**At the turn of the C21st, Harding attempted to portray the daily social life of PwP. He claimed that *'being a Parkinson's patient***

*involves the experience of being locked inside homes as well as selves'* (Harding, 2000:68). This striking portrayal of loneliness was repeated again by Van der Bruggen and Widdershoven (2004:297) who confirmed that for PwP, *'being ill is an isolating experience'*. Such social isolation is likely to lead to a deterioration in quality of life, and reduced wellbeing, not only for the person with PD but with knock-on effects on other family members, most noticeably immediate family carers.

More than three decades ago a sociologist working in the USA pinpointed how PwP might experience a phenomenon she labeled *'premature social ageing'*<sup>3</sup> (Singer, 1974, p143). This is seen when PwP have a reduction in social activities and also fewer significant friendships than their peers; in fact, their social lives more closely resemble those of a person several years their senior. Singers' findings were replicated in a UK context by Oxtoby (1982), who noted that PwP were more likely than most to be occupied in sedentary, passive activities such as watching television or listening to music. Although these pioneering studies were revelatory in their findings, to date, little has changed, and there is still a need for both action and research that addresses the psycho-social privation of PwP.

In response to a perceived need for more activities for PwP in his region, the recently retired, North West regional representative of the PD Society<sup>4</sup>, developed a number of initiatives for members. For those involved, a most successful and enduring activity was, what was originally called, the Annual Holiday Week he organized for 14 years in a Blackpool hotel. This received full support from PDS

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<sup>3</sup> Singer noted that her population had fewer close friends than their healthy peers, had fewer social contacts, fewer leisure activities, and were more confined to their homes too. She found that, typically, people aged 50 with PD, had similar social calendars to those aged 70, in full health.

**members and their families, from inception until the present day. Over the years the Blackpool Week evolved to become a time and place where PwP could come, with or without friends or family, to see a variety of therapists (who give their time voluntarily) and take part in the non-medical therapies which are offered amidst social events. The number and range of therapies on offer has increased and it has become, not just a holiday, but the opportunity to engage in an intensive, holistic therapy programme over a week in Blackpool. It is now known as the Holistic Therapy Programme.**

**Whilst it can be anticipated that this week by the sea would be of general benefit, and despite its anecdotal success, the activity has never been evaluated, and claims for its success stand without validation. Additionally, there has been no attempt to explore just what aspects of wellbeing different parts of the programme address, nor to explore any lasting effects of the programme on people's expressed quality of life.**

**This study set out to carry out an exploratory, psycho-social evaluation of the 2006 holistic therapy programme. In particular it sought to explore the overall and specific impact of the holistic therapies week on participants with Parkinson's, their families and the volunteer therapists, in order to both understand what impact it has on participants, and also to make recommendations for how the experience may be enhanced in the future. The aims, as articulated, were as follows:**

#### **2.4: Stated Research Aims:**

- 4. To gain information about different groups(PwP, carers, volunteer therapists) of participants' reported positive and negative experiences of different activities on offer during the holistic therapy week, in terms of their wellbeing (satisfaction and pleasure as well as personal development and growth);**

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<sup>4</sup> Mr Ian Prest

5. To assess the extent to which gains in terms of quality of life, or wellbeing through participating in the in the week last over time;
6. To provide information that will lead to the enhancement of future holistic therapy weeks as well as the viability of holistic therapy programmes for use elsewhere.

## **2.5: What was the 2006 Holistic Therapy Week?**

The 2006 Holistic Therapy Week took place between October 29<sup>th</sup> and November 5<sup>th</sup> 2006. As previously detailed, an annual Holistic Therapy Programme has been held in Blackpool for the past 14 years and, traditionally, has been so enthusiastically received by PwP that, anecdotal accounts tell of people paying the deposit for the following year, as the current one comes to an end. At all times the Week has been used both therapeutically and psycho-socially, with volunteer therapists staying in the same hotel as the PwP and their families and, customarily, joining in with the evening entertainment and quizzes. None of the participation is compulsory, and there is no explicit expectation of participation by all, in all activities. However, successive years have seen more and more involvement by the attending therapists; this seems to be greatly appreciated by the PwP and their families/carers.

For the first time for 2006 the Carousel Hotel was booked (see photo in Figure 2.2 below), offering good standard accommodation and accessible facilities.

**Figure 2.2: The Carousel Hotel, Blackpool**

Error! Unknown switch argument.

*'The newly refurbished Carousel is the highest AA rated 3 star hotel in Blackpool, and being situated five minutes from Blackpool Airport,*

*it is ideally located on Blackpool's premier South Promenade close to all of Blackpool's attractions yet are far enough away from the bustle of Blackpool's famous Golden Mile to offer a relaxing, refreshing and high quality experience. The Carousel Hotel reopened in March 2004 after being completely renovated, offering 92 en-suite bedrooms'* (sleepwellhotels.com).

**Figure 2.3: Typical double-room facilities at the Carousel**

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The hotel bedrooms (Figure 2.3) were relatively easily reached either by direct access or by using the hotel lift. The en-suite facilities ensured privacy and ease of access for partners or nurses, should the latter be needed to help with showering, bathing or dressing. The nurses were on duty throughout each night so that problems with drug fluctuations, dyskinesias, dystonia or simply with mobility could be resolved on the spot.

There was a well-appointed dining room which served breakfast from 7:00am to 10:30 each morning; this flexibility helped diners co-ordinate their drug regime with meal availability. Figure 2.4 below shows the dining room immediately before dinner, which again was served over an extended time period.

**Figure 2.4: Dining at the Carousel**

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The hotel was fully-adapted for wheelchair access and was disability-friendly in facilities and perhaps more importantly, in staff attitude. Overall, the venue provided an enabling environment

**which doubtlessly contributed to the wellbeing of the guests. The out-sized Ballroom with Bar was singularly successful as: a venue for various therapies (including physiotherapy); a climate-controlled viewing platform for those wanting constant sea views; a perfect meeting place for those wishing to socialise both day and night; a gathering place for the quiz teams. It was also ideally suited to showcase the professional evening entertainment provided each night.**

#### **2.5.1: Daily Therapies and Activities Available During the 2006 Holistic Therapy Week at Blackpool**

**(These are shown in chronological order, with 'reflection time' starting immediately after breakfast each day, and 'evening entertainment and dancing', completing the activities each night in the ballroom and bar).**

- 1. Daily 'quiet reflection' time**
- 2. Physiotherapy (indoors)**
- 3. Exercise Therapy (indoors and out)**
- 4. Speech and Language Therapy**
- 5. Massage Therapy**
- 6. Beauty Therapy (including manicures, pedicures and hairdressing)**
- 7. Daily lecture sessions with invited speakers including PD Nurses, employment specialists, physiotherapists etc.**
- 8. Carers discussion groups**
- 9. Evening quizzes**
- 10. Evening entertainment and dancing**



At all times during the above activities there was a team of four general nurses available for help and support. They provided 24 hour cover.

## **2.6. Participants in the 2006 Holistic Therapy week at Blackpool**

The Carousel Hotel has a maximum capacity of 150 people. During the therapy week some bedrooms were occupied by holidaying families. 20 beds were taken by Therapists, 50 by family or carers of PwP, and the remaining 50 were booked by PwP. The different participants in the week were as follows:

	People with Parkinson's	50
	Family/carers	50
<b>Total number of beneficiaries:</b>		<b>100</b>
<b>Volunteer therapists:</b>	<b>Physio/Speech therapists</b>	<b>5 (3+2)</b>
	<b>Nurses</b>	<b>4</b>
	<b>Massage/beauty etc.</b>	<b>8 (non-residential)</b>
	<b>Visiting speakers</b>	<b>3</b>
	<b>Counsellors</b>	<b>2</b>
	<b>Management</b>	<b>5</b>
	<b>Researcher</b>	<b>1</b>
<b>Total number of organisers and volunteer therapists (residential):</b>		<b>20</b>

## **3. The Evaluation.**

The psycho-social evaluation included information collected in different ways, including through questionnaires, interviews and group discussions. The researcher was also a resident throughout the week and was able to make additional observations. There were two research stages and an audit.

**Stage 1: Semi –structured interviews and group discussions were held with participants (people with Parkinson's disease, volunteer**

**therapists and family members). These enabled perceptions, expectations and experiences of the holistic therapy programme to be explored.**

**Interviews were conducted using a semi-structured format. The topic areas for the interview were developed from discussion between the researcher and people who had attended previous therapy weeks. Small adaptations to the topic areas were made for volunteer therapists and family member interviews, but these were substantially the same in order to allow for differing perspectives on the same topics to be gained (see Appendix 1). All interviews were recorded**

**Stage 2: A quasi-experimental (pre-post-follow up) study was carried out of changes to overall self-reported quality of life before, during and following the holistic therapy week for participants with Parkinson's disease. Overall quality of life, as well as the different domains ( i.e. mobility; activities of daily living, emotional wellbeing stigma social support; cognition; communication ; and bodily discomfort) were measured by the PDQ39.**

**The decision to use the PDQ39 to measure QoL was made primarily because this questionnaire was generated in consultation with PwP<sup>5</sup>..**

**It was originally intended to collect PDQ 39 data at the end of the therapy programme and one month later. However, it proved impossible to gain the data at the end of the week. In the event, the self-reported data on quality of life was collected one week prior to**

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<sup>5</sup> Peto and colleagues used semi-structured interviews with 20 PwP from an out-patient neurology clinic to produce the domains of the questionnaire. The sample size was determined by the responses of the interviewees; the interviews were concluded when data saturation point had been reached. Three researchers then independently devised the questionnaire from the transcribed interviews.

**attending the programme and at the two months following the holistic therapy programme.**

**The audit: The numbers of people attending the different programmes on offer during the week were tallied.**

### **3.1: Research Materials**

- **List of interview topics (see Appendix I)**
- **Introductory letters to explain the research to PwP (see Appendix II)**
- **PDQ39 Quality of Life Questionnaires with the 'About You' cover sheet stapled to questionnaires for extra demographic information (see Appendix III)**
- **Before interview each person signed a consent form (see Appendix IV).**
- **Small, portable cassette recorder (Sony TCM-939) with microphone attached (Ficomp-202) for interviews in quiet surroundings.**
- **Technics stereocassette deck, RS-BX404 and extra sensitive microphones (YT34) for areas with strident extraneous noise.**
- **All tapes and equipment were tested prior to each interview (50 double-sided tapes taken).**

### **3.2: Ethical Considerations**

**The research was undertaken within the Ethical Guidelines of the British Psychological Society. The proposal was approved by the Ethics Committee of the Manchester Metropolitan University, Faculty of Health, Social Care and Education<sup>6</sup>. A key feature of the ethical safeguards was the assurance that all data would be treated**

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<sup>6</sup> Participants were not recruited through their status as NHS patients, all volunteer therapists were present in a voluntary capacity, and the site of the research was a public site, therefore ethical approval through the NHS ethical approval system was not appropriate.

**anonymously and that confidentiality would be preserved. It was stressed that involvement was voluntary and that withdrawal from the study could take place at any time.**

### **3.3: Recruitment to and Participation in the Research**

**All those PwP who had booked to attend the holistic therapy week were written to prior to the activity, to inform them of the evaluation (see Appendix V). In addition, 50 PDQ39 questionnaires were posted to the homes of PwP in the week preceding the therapy week<sup>7</sup>**

**On Monday October 30<sup>th</sup>, during the afternoon lecture slot (see section 2.5.1), all the people attending the Week were invited to attend a one hour session where the evaluation research would be outlined. Although this was spoken of as a 'lecture period', the notices in the foyer of the Hotel made it clear that it would be a 'question and answer' session where those attending would be actively encouraged to be partners in the research process. During the meeting all the background to the research proposal was explained, and issues such as confidentiality and anonymity were explored by those in attendance. Much emphasis was put on the fact that there was no obligation to take part in the process, as well as confirmation that the *people* with Parkinson's would be central to the entire study. Those who attended the session were then invited to consider whether they would like to take part in the interview stage, and if they decided to do so, were asked to volunteer to the researcher in person. From that point onwards, the researcher was inundated with requests to be interviewed. The final number of participants in interviews and discussions are shown in Table 3.1.**

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<sup>7</sup> Mailing list supplied by President of the Holistic Therapy Programme Steering Group

**Table 3.1: Number of people taking part in interviews and discussions by group of attendee**

<b>Group of attendees</b>	<b>No.</b>	<b>Involvement rate</b>
<b>PwP</b>	<b>30</b>	<b>60% of those attending, residential</b>
<b>Carers/family</b>	<b>18</b>	<b>35% of those attending, residential</b>
<b>Volunteer therapists</b>	<b>12</b>	<b>55% of those attending</b>

### **3.4: Data collection**

#### **Stage 1:**

**All participants in the week received an information sheet about the research, in advance of arriving at Blackpool (See Appendix V), thus giving ample time for consideration of the research and potential involvement. No interviews were undertaken on the first day, allowing people time to settle into the programme. Interviewing started on the morning of Tuesday October 31<sup>st</sup> and continued until 8:00 pm on Friday November 3<sup>rd</sup>.**

**An effort was made to ‘*use interviews ... as a ‘directed conversation’ and not as a closely controlled, monitored and measured pseudo-experiment*’ (Richardson 1997, p89). Informed written consent was obtained before each interview, and generally about five minutes were spent ‘*observing at least some of the rules of politeness of human dialogue and social interaction as a first step to facilitating a smooth flow of the exchange of information*’ (ibid, p89), in effect, to build a rapport. People were assured that they could stop the interview at any time, re-schedule if they wished, take time-out during a talk and recommence later, decline to answer any questions they were not comfortable with, or come back to specific questions later. The researcher made it clear when the tape recording was actually commencing, and constantly checked if the interviewee was feeling OK, whilst recording continued. When interviews ended, explanations were given to people as to exactly**

what happened to 'their' tapes. Interviews took between 5 and 45 minutes and each interviewee was thanked for their assistance.

## **Stage 2:**

50 PDQ39 questionnaires were posted to the homes of PwP in the week preceding the Therapy Week. Because the data from the three planned stages<sup>8</sup> of questionnaire administration would need to be accurately matched, and additionally so that a body of demographic data about those who attended the Week could be assembled for possible later use in research, there was an 'About You' top sheet appended to each questionnaire ( see Appendix III). A second batch of PDQ39 forms was distributed at the end of the Week, and the final, follow-up questionnaires were distributed two months after the end of the programme (early January 2007). Once data had been entered into an SPSS spreadsheet, all identifiers were removed from the questionnaires.

Of the 50 Quality of Life questionnaires were distributed in the week preceding the Therapy Week, and 45 (90%) were handed in at the reception desk of the Carousel Hotel during the course of the Holistic Week. 50 were again distributed on the morning of departure from Blackpool, together with stamped addressed return envelopes. Follow-up phone calls were made to encourage return of this second batch of PDQs, but response rate remained poor. The final 50 (again with stamped return envelopes) were sent in the second week of January 2007. Originally, the proposal was to distribute the third set of questionnaires *one* month after the Therapy Week, but because the response was so poor to the second batch, a decision was taken to wait until after Christmas and New Year before posting the last batch. Given that 75% of these were actually returned, it seems that the judgement was indeed helpful.

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<sup>8</sup> In the event, two stages only: at the start of the week and two months after the week

**See Table 3.1 for response rate of return of questionnaires at different time points.**

**Table 3.2: Questionnaires distributed and returned at different stages of the study**

<b>Time:</b>	<b>No. distributed</b>	<b>No. returned</b>	<b>Response rate</b>
<b>Prior to Holistic Therapy Week</b>	<b>50</b>	<b>45</b>	<b>90%</b>
<b>End of Holistic Therapy Week</b>	<b>50</b>	<b>8 by end December</b>	<b>16%</b>
<b>Two months following Holistic Therapy Week</b>	<b>50 sent out January 2007</b>	<b>35 by end February 2007</b>	<b>70%</b>

### **3.2.5: Data Analysis:**

#### **Stage 1:**

**Each of the semi-structured interviews was recorded and transcribed, and pseudonyms were allocated to all the co-researchers, as well as to any third parties mentioned in the interviews. Hierarchical thematic analysis was undertaken according to qualitative research recommendations made by Ryan & Bernard (2005) who noted that: '*the simplest and most direct indication of schematic organization in naturalistic discourse is the repetition of associative linkages*' (p2). By choosing interviews and analysing them by thematic analysis, a commitment is made, not to truth as an absolute, but to truth as defined by the person speaking, and within the context of their own life (Probyn, 1990). Through this analysis, over-arching themes and subsidiary themes and linkages between them are identified. Data were scrutinised for common experiences over topic domains and activities as well as differences.**

#### **Stage 2:**

**Returned PDQ39 questionnaires were processed as follows:**

- 1. As each questionnaire was received it was scored and coded.**

- 2. Demographic details were entered on an XL spreadsheet database including: title, name, address, postcode, phone numbers, gender, age at onset, duration of illness, education level, and family history of PD.**
- 3. The responses to each of the questions were entered into the same XL database. The spreadsheet showed 'Question 1 through to Question 40' (thus 40 columns) with the scores given by each individual to that particular question.**
- 4. Incomplete questionnaires were excluded.**
- 5. The data were separated into the 'domain headings' assigned by the compilers of the PDQ39.**
- 6. The questionnaires scores were statistically analysed as a whole group. In order to compensate for multiple statistics testing, a Bonferroni correction was applied, leading to the setting of a significance level of 0.005.**

**The combined tests enabled judgments to be made about what impact attending the weekly programme has, over time, on different aspects of wellbeing or quality of life for the group of people with Parkinson's Disease as a whole.**

### **3.3: The interviewees**

**30 people with Parkinson's participated in semi-structured interviews.**

**Table 3.3 gives a breakdown of participants by gender, age, duration of illness, co-morbid conditions, occupation, marital status, family history of PD and level of education.**



Table 3.3: Details of Interviewees with Parkinson's (N = 30)

Pseudonym	Age Dgns	Dur of PD	Other Maj Ill	YO / OO	Retired due to PD	Employment	Marital State	Family Hstry	Education
Joseph	67	8	No	OO	No	Management	Married	Yes	Tertiary
Clive	67	4	Yes	OO	No	Management	Married	No	Tertiary
Arthur	55	12	No	YO	No	Entrepreneur	Married	No	Tertiary
Daniel	45	8	No	YO	No	Deliveryman	Married	Yes	Tertiary
Julian	54	8	Yes	YO	Yes	Policeman	Married	No	Secondary
Maria	53	13	No	YO	Yes	Shop assistant	Divorced	No	Secondary
Joel	60	10	No	OO	Yes	Sports coach	Married	No	Tertiary
Giles	60	14	Yes	OO	No	Director	Married	No	Tertiary
Mitzi	72	8	No	OO	No	Housewife	Married	Yes	Secondary
Graham	48	18	No	YO	Yes	Architect	Married	No	Tertiary
Matthew	52	14	Yes	YO	Yes	Lawyer	Married	No	Tertiary
Maud	72	4	No	OO	No	Housewife	Widowed	Yes	Secondary
Norris	64	9	Yes	OO	No	Farmer	Married	No	Secondary
Gerald	70	5	Yes	OO	No	Driver	Married	No	Secondary
Theodore	75	8	Yes	OO	No	Journalist	Married	No	Tertiary
Beatrice	82	1	Yes	OO	No	Hairdresser	Divorced	No	Secondary
Charles	72	7	No	OO	No	Military Officer	Divorced	No	Secondary
Edith	72	14	Yes	OO	No	Secretary	Widowed	No	Secondary
Joshua	55	12	No	YO	No	Civil servant	Married	No	Secondary
Deborah	57	14	No	OO	No	Housewife	Married	No	None
Jonathan	60	10	Yes	OO	No	Insurance Clk	Married	No	Secondary
Jocelyn	73	8	Yes	OO	No	Clerical Asst	Widowed	No	Secondary
Ernest	78	6	Yes	OO	No	Indust Technic	Married	No	Tertiary
Deirdre	51	18	No	YO	No	Secretary	Single	No	Secondary
Sally	42	18	No	YO	Yes	Packer	Married	No	Secondary
Raymond	59	9	No	OO	No	Driver	Married	No	Secondary
Janine	?	?	No	?	No	Housewife	Widowed	No	Secondary
Beulah	62	11	No	OO	Yes	Librarian	Widowed	No	Tertiary
Dick	42	20	No	YO	Yes	Electrician	Married	No	Secondary
Gerald	45	29	No	YO	Yes	Builder	Married	No	Secondary

## KEY:

§ Pseudonym	=	The pseudonym given to ensure anonymity for P's.
§ Age Dgns	=	Age when PD diagnosed.
§ Dur of PD	=	Time, in years, that the person has had PD.
§ Other Maj Ill	=	Other major illnesses which may complicate the management of PD. Eg. heart disease, diabetes.
§ YO/OO	=	Whether the person was under 55yrs at diagnosis, young onset [YO], or over 55yrs [OO], old onset.
§ Retired due to PD	=	Whether the person has retired from employment.
§ Employment	=	How the PwPD describes their employment.
§ Marital State	=	Single, married, separated, divorced, as married.
§ Family History	=	States whether person has any relative with PD.
§ Education	=	Includes primary, secondary or tertiary only.

As the Table indicates, 18 men were interviewed and 12 women. Of those listed, 11 were diagnosed with Parkinson's before the age of 55 (thus Young Onset PwP), and of the 11, nine people took early retirement as a direct result of their diagnosis. 12 people had serious co-morbid conditions, 21 were married, 3 divorced, 5 widowed and one person was single. 11 PwP were educated to degree level, and the mean age of those interviewed was 71.9yrs. The mean age of Parkinson's onset for the interviewees was 60.82, which is broadly in line with global statistics (NINDS, 2006) and the mean duration of PD was 11.03 years.

In the original proposal for evaluation of the Holistic therapy week, it was projected that just eight family members or accompanying carers would be interviewed about their own experience of the Week. Over the course of the week though, it became clear that many of the helpers actually wanted to 'have a voice' and put their own (frequently very strong) views on record. A decision was taken to include as many people who wanted to participate as possible, and consequently the opinions of 18 people *without* Parkinson's were recorded.

Of those carers who were interviewed, (see Table 3.4), 12 were wives of men with PD, two were husbands carers, and one daughter took part too.

**Table 3.4: Details of Partners/Carers Interviewed (N = 18)**

Pseudonym	Where Interview took place	Time of Interview	Date	Attended with?	Relationship
Julia	Ballroom	6:30pm	Nov 3rd	Gerald	Wife
Annie	Ballroom	6:45pm	Nov 3 <sup>rd</sup>	Theodore	Wife
Hazel	Ballroom	6.50pm	Nov 3 <sup>rd</sup>	Beatrice	Friend
Jean	Sunroom	11:00am	Oct 31 <sup>st</sup>	Norris	Wife
Dilys	Breakfast room	10:15am	Oct 31 <sup>st</sup>	Julian	Wife

Vanessa	Bar	11:00am	Nov 3 <sup>rd</sup>	Matthew	Wife
Sheila	Bar	11:10am	Nov 3 <sup>rd</sup>	Graham	Wife
Donald	Sunroom	2:00pm	Nov 2 <sup>nd</sup>	Mitzi	Husband
Jennifer	Breakfast room	10:00am	Nov 2 <sup>nd</sup>	Joel	Wife
Louisa	Bar	12 noon	Nov 2 <sup>nd</sup>	Clive	Wife
Sophia	Treatment Room	6:00pm	Oct 31 <sup>st</sup>	Geoffrey	Wife
James	Treatment Room	6:15pm	Oct 31 <sup>st</sup>	Dorothy	Friend
Olivia	Treatment Room	6:30pm	Oct 31 <sup>st</sup>	Donald	Wife
Amanda	Treatment Room	7:00pm	Oct 31 <sup>st</sup>	Peter	Wife
Suzie	Treatment Room	7:15pm	Oct 31 <sup>st</sup>	Mary	Friend
Gareth	Treatment Room	7:30pm	Oct 31 <sup>st</sup>	Maria	Husband
Pauline	Treatment Room	7:45pm	Oct 31 <sup>st</sup>	Emily	Daughter
Spencer	Treatment Room	5:30pm	Oct 31 <sup>st</sup>	Hannah	Wife

**Table 3.5 provides the details of the various therapists who were interviewed and shows that four nurses made themselves available , three physiotherapists, two beauticians/massage therapists, one general helper and just five minutes was spent with the one speech and language therapist. The general helper, a middle-aged man married to one of the nurses, proved himself invaluable at those times when physical strength was required. He assisted with the movement of wheelchairs, motorised scooters and other physical aids that PwP brought with them, as well as giving generous help to those with severe movement difficulties. Most especially, he was expert at supporting PwP who stumbled and were likely to fall, and indeed lifting those who did fall.**

**Table 3.5: Details of Therapists Interviewed (N = 12)**

Pseudonym	Where Interview took place	Time of Interview	Date	Type of therapist
Christina	Ballroom	10:30am	Nov 3 <sup>rd</sup>	Counsellor
Martin	Dining room	2:15pm	Nov 2 <sup>nd</sup>	Nurse
Theresa	Dining room	2:15pm	Nov 2 <sup>nd</sup>	Nurse
Marie	Dining room	2:15pm	Nov 2 <sup>nd</sup>	Nurse
Mandy	Dining room	2:15pm	Nov 2 <sup>nd</sup>	Nurse
Bethany	Ballroom	1:00pm	Nov 2 <sup>nd</sup>	Physiotherapist
Kelly	Ballroom	1:00pm	Nov 2 <sup>nd</sup>	Physiotherapist

Aaron	Ballroom	1:00pm	Nov 2 <sup>nd</sup>	Physiotherapist
Katy	Treatment room	5:00pm	Nov 2 <sup>nd</sup>	Beauty therapist
Hayley	Treatment room	5:20pm	Nov 2 <sup>nd</sup>	Beauty therapist
Sophie	Bar	12 noon	Oct 31 <sup>st</sup>	Speech/Language
Tony	Bar	5:00pm	Oct 31 <sup>st</sup>	General helper

## 4. The Impact of the Holistic Therapy Programme on Participants

The findings of the evaluation will be organised around the different activities, followed by general comments on the impact of the week on different participants.

Detailed information about who attended which sessions was not kept, but numbers attending were tallied (Table 4.1).

**Table 4.1: Audit of Therapies and Activities offered – numbers of people attending different sessions each day**

Activity / Therapy	Monday	Tuesday	Wednesday	Thursday	Friday
Quiet reflection time	52	61	65	68	73
Physiotherapy	47	52	53	54	63
Exercise therapy	8	12	12	18	12
Speech therapy	16	-	-	-	-
Massage therapy <sup>9</sup>	92	84	88	85	71
Beauty therapy <sup>10</sup>	74	82	80	79	97
Lecture sessions	48	62	42	28	-
Carer's forum	-	24	-	27	-
Quizzes	14 teams	14 teams	14 teams	14 teams	14 teams
Entertainment / dancing	Approx 36	83	80	80	110

<sup>9</sup> In attendance for the entire week was a team of eight beauty/massage therapists (seven female and one male) who offered a 20 minute time slot from 10:00am to 5:0pm each day. Every slot was booked for the entire week and there was a 'reserve' list in case of cancellations.

<sup>10</sup> At the hotel, manicures, pedicures and facials were on offer. The rise in the numbers for Friday reflects the interest in the celebratory Gala Dinner scheduled for that evening. Additionally, at the local FE College a team of hairdressers worked for the full week for the Carousel guests. They too were inundated on the Friday, although no audit was kept of any of the hairdressing appointments as clients were transported from hotel to college by minibus and proved impossible to track.

**It should be noted that some of those people recorded in activities from Tuesday onwards were repeat attendees. For instance, the numbers taking part in the morning physiotherapy sessions, although increasing day by day, represent a core of people who attended all sessions. There is no information about numbers of people who did not attend any sessions.**

**Perhaps the most useful way to view the audit is to consider each activity, and look at the audit figures in conjunction with what participants said about the impact of the activity, along with the statistical results from the PDQ39 questionnaires. The Various questions of the PDQ39 reflect different domains of activity which can be aligned with the activities on offer during the Holistic Therapy Week. Thus, PDQ39 data will be summarised as relevant to each activity. The domains are: mobility; activities of daily living; emotional wellbeing stigma social support; cognition; communication ; and bodily discomfort. Experiences of different activities will follow the order of Table 4.1.**

#### **4.1: Quiet Reflection time**

**Reflection sessions, at the start of each day were facilitated by Christina who is registered as both a General Nurse and also as a Counsellor. She has attended 14 of the 15 Therapy weeks at Blackpool, originally accompanying her Father who had a diagnosis of Parkinson's.**

**Those who were interviewed at Blackpool only had positive things to say about the 'reflection time'. The number of people who made the effort to get to these relatively early morning sessions seemed to present fairly compelling evidence of the value PwP attached to these gatherings. As Vanessa so clearly put it:**

***"It probably looks a bit naff, but it can't***

162). *be naff when 60 people want to attend...'* (Lines 157-162).

And in the words of Maud, a widow who attended as part of a group from her PD Society Branch:

*"Well, I'm rather a tense person. (But here) I find I relax ... and I feel peaceful. ...It's this thing of peace. A calming of the Parkinson's "* (Lines 198-201).

The overall questionnaire scores, however, did not reveal any statistically significant change between prior to coming on the programme and two in the relevant domain linked to the reflection activity, namely emotional wellbeing (Table 4.2). The trend in the data was to a deterioration of emotional wellbeing over this time. This may be linked to the degenerative nature of PD, but most likely, over this two month period to the anti-climax of returning home following the anticipation of the week to come.

**Table 4.2: Mean scores for Emotional Wellbeing (7 items) before (Time 1) and two months after (Time 2) attending the Holistic Therapy Week**

	Mean	N	Std. Deviation	Std. Error Mean
Time 1 Sum of Emotional Wellbeing	17.2581	31	5.72694	1.02859
Time 2 Sum of Emotional Wellbeing	19.8065	31	11.05568	1.98566

For this activity then, there is a lack of congruence between the questionnaire findings and the interview data. The PDQ39, over a two month period, did not pick up the positive impact the activity had on participants at the time.

#### 4.2: Physiotherapy

Few PwP doubt the benefit of regular physiotherapy as evidenced by the numbers who attended throughout the week (total 269 sessions

over the five days). The sessions were led by a team of physiotherapists (including two young and newly qualified people) with a leader trained in neurological physiotherapy and the specific needs of PwP. The improvements in movement that so many PwP demonstrated over the week at Blackpool cannot simply be the result of regularly attending the morning sessions; they are too extreme. As Arthur, a man with Parkinson's said, of a friend who regained substantial mobility during the week following daily group physiothereapy:

***" We really need to make clear that Matthew has not been walking outside for at least a year ... yesterday he managed a block..."***(Arthur, Lines 345-360).

Bethany, the neuro-physiotherapist, was clear as to how such changes could be effected though:

***"I think we forget how closely the motor and psychological aspects are ... think where the basal ganglia is situated, and it's bang next door to the limbic system ... You cannot separate motor control from psychological influence"*** (Bethany, Lines 108-111).

This explanation is in line with a report published by Fricchione and Stefano (2005) who claim: *'the expectancy associated with treatment ... may raise endogenous dopamine levels, thus overcoming some of the motor aspects of Parkinson's'*(p3). If the findings of Fricchione and Stafano were extrapolated to the Therapy Week, their *'expectation model'* suggests that the brain's *'reward system'* may be influenced by such amorphous psychological constructs as *'confidence'* and *'social support'* and that could result in what they refer to as *'a psychologically-induced release of endogenous dopamine'*.

The domain within the PDQ39 of most relevance to physical mobility is the 'activities of daily living' domain. There was no statistically significant change in activities of daily living between prior to the therapy week and two months later (Table 4.3). Data are not available for any change immediately following the week. However, observation suggests there was substantial increased mobility at this time, highlighting the importance of maintaining a routine of targeted mobility exercises, and the importance of clear guidelines from physiotherapists about how such routines can be maintained at home.

**Table 4.3: Mean scores for Activities of Daily Living (7 items) and Mobility (9 items) before (Time 1) and two months after (Time 2) attending the Holistic Therapy Week**

	Mean	N	Std. Deviation	Std. Error Mean
Time 1 Sum of Activity of Daily Living	21.0286	35	7.99811	1.35193
Time 2 Sum of Activity of Daily Living	20.9714	35	7.47343	1.26324
Time 1 Sum of Mobility	27.4286	35	9.72954	1.64459
Time 2 Sum of Mobility	28.4571	35	12.67546	2.14254

In addition to physiotherapy, some people attended general exercise sessions.

#### **4.4: Exercise Therapy**

Fewer people opted for this therapy than for physiotherapy, which possibly reflects the general health state of many of those who attended Blackpool. Only those who were still able to walk independently, or partially supported (by partners, physiotherapists or nurses), took part in the walking and swimming sessions. The Blackpool location was particularly well-suited to general exercise in that there are many long, flat stretches of promenade that can be used. Like physiotherapy, the exercise sessions could benefit both the 'mobility' and 'activities of daily living' fields, so Table 4.3 is



relevant here too. Aaron, a newly-qualified physiotherapist outlined how the exercise programme ran:

*“We provide activities during the day ... to test out what they can do. We’ve run swimming twice and walking every day. They gain confidence here, then go back home with that”* (Aaron, Lines 127-130).

Whilst Bethany described them thus:

*“The exercise classes? The first day ...it was mainly sitting and ‘freeing up’ ...by today we have had an absolutely raucous, standing team event that ... you know, people were running ”* (Lines 266-270)

If the lives of PwP were improved to the extent that they could take part in a ‘standing team event’ following five days of exercise and physiotherapy, then clearly there was some improvement in functioning that was not picked up by the PDQ39. In future years it might be useful to take actual physical measures of mobility at the start of the Holistic Therapy Programme and again on the Friday afternoon before the Gala Dinner. The mechanisms of change so valued by PwP, as reported in the interviews, need to be unpacked in full so that other people with long-term neurological conditions might profit.

#### **4.5: Speech and Language Therapy**

In 2006 only 16 PwP worked with the speech and language therapists (SLTs) who were present during the Monday morning only. During the planning of the Holistic Therapy Programme a number of universities were asked if they had undergraduate SLTs who might be interested in training during this Week, but there was a poor response to the invitation.

Table 4.4: Mean scores for Communication (3 items) before (Time 1) and two months after (Time 2) attending the Holistic Therapy Week

	Mean	N	Std. Deviation	Std. Error Mean
Time 1 Sum of Communication	7.4571	35	2.79014	.47162
Time 2 Sum of Communication	7.7714	35	3.21838	.54401

**Table 4.4 shows that there was no significant change in the scores for the 'communication' domain from the PDQ39 over the weeks. As explained above, the data are for the whole group and not just for those who attended speech and language session. They will almost certainly obscure any benefits those who participated in the sessions might have gained. For the 2007 Week (which is already taking bookings) it is imperative that more SLTs, and student therapists, are recruited, so as to make these sessions more widely available. During a full week it would be possible for PwP to receive a full 'course' of training in speech and language. Equally important for the future, is that a more undergraduate SLTs would be exposed to Parkinson's and, through this exposure, could possibly develop a career working with PwP.**

#### **4.6: Massage and Beauty Therapy**

**The numbers of those who availed themselves of these services have been extracted from the audit table (shown in Table 4.2) and repeated here to emphasise precisely how well-received these treatments were (see Table 4.5)**

**Table 4.5: Audit of Beauty and Massage Therapies offered**

Activity / Therapy	Monday	Tuesday	Wednesday	Thursday	Friday
Massage therapy	92	84	88	85	71
Beauty therapy	74	82	80	79	97

**Keeping in mind that the hairdressing appointments are not included in Table 4.5, it is clear that the treatments offered were something of great value to both PwP and their families or carers.**

Following some of these sessions, Anne noted an improvement in her mother.

*"I haven't seen my Mum put her hand up like that (lifting own arm high in the air), in about two years... (Anne, mid 50s teacher, both parents with PD, Lines 322-326).*

To an outsider, the concept of 'beauty therapy' for people with long-term health conditions might seem frivolous, or a waste of time and resources. But those attending the Week saw the presence of a beauty team as a huge advantage. Joseph could not find the words to describe *how* he benefited from an Indian head massage, but, he leaves an indelible image of how much he enjoyed it:

*"I have had an Indian head massage. I loved it. I nearly put her in my suitcase. It helps my Parkinson's ...I would be hard put to explain how ... a blind man on a galloping horse could see the difference"* (Joseph, ex-rugby player, Lines 175-177, 268-269).

Few could argue that Joseph's QoL was not improved by seeing a beauty therapist, but for Daniel, it was not his own pleasure that was pre-eminent. As a very young man with PD, he seemed to be ever conscious of the stresses and strain his PD puts on his wife and children, so for him, it was really important that some treatments were available for his wife.

*...my wife gets spoiled for a week. She had her hair done this morning .... You see, somebody watches your patient and you watch theirs while they go somewhere ..."* (Daniel, Lines 175-181, 314-5).

Here Daniel is referring to himself when he mentions others watching '*your patient*' and is talking of how his wife could relax in the hair salon knowing that Daniel was not alone in the hotel. This is an advantage of the Week that should not be underestimated by people who do not have caring responsibilities, and indeed was spoken of by many of the cares in attendance.

Within the PDQ39 is a construct called 'bodily discomfort' and it is into this domain that the massage therapy would naturally fit. The scores for the construct are shown in Table 4.6.

**Table 4.6: Mean scores for Bodily Discomfort (3 items) before (Time 1) and two months after (Time 2) attending the Holistic Therapy Week**

	Mean	N	Std. Deviation	Std. Error Mean
Time 1 Sum of Bodily Discomfort	8.3429	35	2.65621	.44898
Time 2 Sum of Bodily Discomfort	8.6571	35	3.16175	.53443

Again, there was no significant change in the mean scores of this domain (encompassing such nebulous symptoms as aches, pains, cramps, and spasms), and the PDQ39 is not sufficiently discriminatory as to identify the benefits that PwP described in their interviews. Future work should possibly focus more on self-efficacy rather than quality of life, or, alternatively, should measure actual physical states such as 'ability to lift arm above head', rather than self reports of bodily discomfort.

#### **4.7: Lecture Sessions**

The lecture sessions were well attended every day. The people who attended the lectures talked in positive terms about their involvement. One younger woman with PD said:

***"I learned a lot here. If this was anywhere, I'd go. It's the information you pick up ..."***  
(Sophia, Lines 331-347).

And an interesting point about their lasting impact was made by Aaron when he noted that:

***"Actually, this is a great way to disseminate [information] to a lot of people ...quite compact, one week only. Beth is able to disseminate to maybe several dozen people, and they can go home and work with that".*** (Aaron, physiotherapist, Lines 67-70).

The concept of the Holistic Therapy Programme does allow for communication with many PwP (plus their respective families or carers) at the same time, and therefore has value for any professional working in the field of PD.

The PDQ39 field that the lecture sessions link with is 'cognitions'. Table 4.7 shows the cumulative means for the four PDQ39 items of relevance here.

**Table 4.7: Mean scores for Cognitions (4 items) before (Time 1) and two months after (Time 2) attending the Holistic Therapy Week**

	Mean	N	Std. Deviation	Std. Error Mean
Time 1 Sum of Cognitions	10.7143	35	3.73829	.63189
Time 2 Sum of Cognitions	11.1714	35	4.14790	.70112

There were 35 questionnaires with the 'cognition' responses completed, but once again, there is no significant change over time. The trend is to a decline in cognitions over the two month period.

#### **4.8: Carer's Forum**

For the first time in the history of the Blackpool Week, the 2006 Week offered two 'carers' forums', where family members, friends or just visitors could talk in confidence to other people with responsibility for a person with Parkinson's. 51 people attended

over the two evenings offered and, on each occasion the Forum only came to an end when Hotel staff asked for access to the room being used. The major benefits reported were linked to the support gained from being with people in the same situation as well as the space for release of pent up emotions. Sophia talked of the benefits of the group:

*"The value to me as a carer? I think it's the fact of 'being in the same boat'; being part of a group of people who have got all the same problems"* (Sophia, Lines 308-309).

Louise used the time for expressing her difficulties and asking for ideas of how to cope.

*"One thing I've found very difficult to cope with – it gets very emotional. I'm so distressed and I don't know how to cope. If any -one's got any suggestions?"* Louise, crying, Lines 754-762).

Although the PDQ39 was completed by PwP, and was not intended to measure QoL for carers, it is possible that the domain of 'social support' might pick up changes in the wellbeing of carers through the perspective of PwP. The mean scores for the domain of 'social support' on the PDQ39 are shown in Table 4.8.

**Table 4.8: Mean scores for Social Support (3 items) before (Time 1) and twom months after (Time 2) attending the Holistic Therapy Week**

	Mean	N	Std. Deviation	Std. Error Mean
Time 1 Sum of Social Support	5.3429	35	2.33821	.39523
Time 2 Sum of Social Support	4.6000	35	2.47576	.41848

There was no significant difference in mean scores fo rthe domain of 'social support over the two time periods. The trend was to lesser satisfaction following the therapy programme. The PDQ39 was not

**a sensitive measure to detect these indirect consequences of support for carers during the week.**

#### **4.9: Evening Entertainment plus Quizzes**

**In addition to the scheduled activities, there were also two evening tours of the Blackpool Illuminations organised, with tram transport arranged from door to door, and supplementary physical help provided for those with mobility challenges. Each of the trams was filled to capacity on each of the visits (approx 32 people per tour).**

**A most successful aspect of the programme were the evening quizzes. These had been compiled by one of the therapists before arriving for the Week and were distributed each evening in the Ballroom immediately after dinner. Teams were formed on the first evening (generally, but not exclusively, around PDS Support Branch groups) and these teams worked together for the whole week. The questions were of the type that might be seen in a general pub quiz (general knowledge, but sub-divided into groups such as 'sport and entertainment', 'geography' etc). Thus the questions were not so difficult as to worry people, but sufficiently challenging as to take a little time to answer. Indeed, where some teams struggled with an answer, they were seen using mobile phones and the internet to source the solutions!**

**The benefit of these activities could be seen primarily in the camaraderie that accrued over the days, but as any PD researcher might recognise, there was also the benefit of repeated cognitive exercise, and the evening quizzes can only be seen as helpful. Hilary, explained how the evening activities affected her:**

***"The value is enormous to my mind. It gets people together, talking to each other ..."*** (Hilary, Lines 77-81).

**In addition to the evening activities, Christina thought that the residential component to the Week was necessary for maximum advantage.**

***"It has to be residential because a lot of the bonding occurs at night, in the evening ... (We) go through all these things (therapies), knowing that all we've got to do is walk up the stairs to bed ... "(Christina, Lines 197-203).***

**Quizzes address the 'cognitions' domain of the PDQ39. As we saw above (Table 4.7), however, there was no significant change in cognitions scores over time, indicating once more that the PDQ39 was not a**

**In the future at the Therapy Week, it would be useful to directly measure cognitive activity for PwP in order to better assess the cognitive advantages of the evening quizzes, independent of the psycho-social gains.**

## **5. Impact of the Intensive Therapy Programme on the Wellbeing of Participants**

**The intensive therapy week had identifiable positive and some not so positive impact on the wellbeing of different groups of participants.**

### **5.1: Positive impact on wellbeing**

**There was no significant change in the Quality of life for those PwP who attended the Therapy Week, as measured by the PDQ39.**

**Despite this statistical result though, the interview data indicated, to a certain extent that there were, indeed, improvements to 'wellbeing'.**



**We have seen, above, that the different activates variously contributed to the enhancement of social and community wellbeing (being with other like-minded people facing similar challenges); physical wellbeing (through increased mobility); leisure (through informal activities); environmental wellbeing (through the facilities and location); and personal wellbeing (anticipation and enjoyment).**

**Less obviously, perhaps, is the contribution the week made to spiritual wellbeing, particularly through the perceived role that 'taking a break' played. The Holistic Therapy Programme played an important part of people's lives. Gerald described it as:**

***"... the first real break we've had since diagnosis"***  
**(Lines3-4).**

**Perhaps the clearest account of why PwP feel they need the therapy week was articulated by Julian, who said:**

***'It's necessary for people to have a break, where they can let their inhibitions go, because we're like-minded people; people who struggle walking, eating and everything else. It's a necessary part of life to have a break'*** (Julian, Lines 287-295).

**Anita stressed the anticipatory aspect of the experience.**

***'...we look forward to this every year ... because we can't go abroad.'*** (Lines 45 and 52).

**Certainly, it seems that the PwP and their family or carers did take the opportunity during the week to 'take positive actions to realign the relationship between body, self and society (Williams, 1996: 32).**

**Family members and carers also benefited from the week. Those**

who accompanied PwP to the Week were not asked to complete any questionnaires about their involvement, they *were* informed of the Carer's Forums, and also invited to take part in interviews about their roles. The number of people who took up these invitations may possibly be seen as a testament to the need for more support for families and carers. From the interview data, there seemed to be two major advantages of the Week. The first was the opportunity it gave them to meet with other carers (social and community wellbeing). The second was the break that family members got from their caring responsibilities, coupled with a lack of guilt that normally accompanied such breaks.

*'The fact that we're given permission to do something for ourselves and not feel guilty that I've left my partner (who has Parkinson's) sat somewhere ...that's been the brilliant thing about this. It gives you time ...' ( Suzie, Lines 342-344).*

Volunteer organisers and therapists had given their time freely, at some personal cost. Information about the benefits they gained were derived from interviews.

The nurses, who were in attendance for the entire week, had all taken holiday leave from their usual posts, and the younger nurses had arranged childcare for the children they left at home. Three of the four nurses and the one male 'helper' had attended previous Therapy Weeks, with one nurse who had worked at 14 of the total 15 held over the years. One nurse did explain that she was interested in becoming a PD Specialist Nurse and was hoping to gain *'more of an insight into it'*, but the main motivation for the volunteers seemed to come from knowing that they were able to make a real difference to the success of the week: they felt that attending was its own reward. Christina (leader of quiet reflection time, and quiz compiler) felt that the best part of the week for her was the laughter between people, together in one place. She spoke

of how, for most PwP too, this was the best way to improve overall wellbeing too. In explanation she said:

*'They've worked hard all their lives, brought the children up, good honest citizens. They've followed all the rules. And they've been cheated of their retirement' But here ... people are laughing at themselves, saying, it's alright that I'm shaking. For most of the year they are a bit ashamed; they are hiding it; they are embarrassed; they don't play a part in society and that. But here, we're all in the same boat ...'* (Christina, Lines 333-338, 353-358).

For the physiotherapy team, there were a number of tangible advantages gained from attending the Week. Kelly outlined the first one:

*'...the CPD side of things ...you're forced to see that they are actually people, because usually you see them in hospital, and they're in their gowns, they're looking pasty and its because there's something wrong, whereas now I get to see them as people, as a couple going about their daily life, and how people really live with Parkinson's. ... I've got more of an idea what it's like really living with somebody with Parkinson's...'* (Kelly, Lines 309-316).

And Aaron, speaking of the visiting (non-residential) physiotherapists, noted the second:

*'They're using it for their own CPD, as part of their own professional development ...'* (Lines 301-302).

For the volunteer therapists, then, amongst experiencing the satisfaction of helping and seeing PsP in a different light, they gained in terms of eudemonic wellbeing, or personal development

## **5.2: Threats to wellbeing**

One possible deleterious effect on some people, of a full week with other PwP is that a negative future may have become clearly delineated. As Maud said:

*'It turns your life upside down. When you first get diagnosed and you see these people ... Popes and all those ... you think, God, that's my future ... it's frightening'* (Lines 7-11).

Another negative account related to confirming that overall, things were not going to get any better, and that the future looked somewhat bleak.

*'I feel like it's me and him against the world. It's like a sentence. The two of us against the world. I don't think there are any quick fixes at all'* (Lousia, Lines 26-28).

But the most noticeable deficit in wellbeing was in connection with one of the organisers of the Week, who continued to organise during the week, and whose PD seemed to visibly deteriorate as the days passed. Aaron, a member of the physiotherapy team, also detected this, but considered that this willingness to become over-stretched reflected the perceived value of the therapy week.

*'I would say his [organiser with PD] health has deteriorated because of his commitment to make this happen. I would say that he's done too much... certainly his relationship with his wife has suffered. I think if people are prepared to do that, it tells you something very precious ...'* (Aaron, Lines 393-401).

## **5.3: Overall impact of the holistic therapies week on people with Parkinson's Disease**

It is clear from the evaluation that the holistic therapy Programme had a positive effect on the wellbeing of people with Parkinson's

**Disease. It is less clear that these effects had any long lasting impact. As we shall see, the evaluation was not sensitive enough to inform this longer term impact.**

#### **Stage One of the evaluation**

**Stage One of the evaluation was an interview based study of different participants' experiences of the therapy week in terms of wellbeing arising from the different activities and the overall week's stay. From the evidence gathered during the 2006 Holistic Therapy Programme there can be little doubt that it enhanced the wellbeing of those who attended, both in terms of different facets of wellbeing (for PwP); on social and community wellbeing in particular for family members and carers; and on eudaemonic wellbeing of volunteer therapists. The general impact for all those who attended was overwhelmingly positive.**

#### **Stage Two of the evaluation**

**Stage two of the evaluation was a quasi experimental investigation of changes in quality of life (measured by PDQ39) over the week and following the week. As previously noted, none of the domains of the QoL questionnaire that mapped onto activities during the week (that is, mobility, activities of daily living, emotional wellbeing, social support, cognitions and bodily discomfort), revealed any statistical change in scores between prior to the week and two months after it.**

**This might indicate that the week had no impact on quality of life of PwP attending it. However, it is more likely that the tool was not an adequate measure of particular changes in quality of life, linked to those activities on offer during the week. As we have seen above, wellbeing may prove to be more useful concept in assessing the impact of the week on participants.**

However, one domain of the PDQ39, not specifically linked to activities during the week, did a change. There was a statistically significant increase in perceived stigma two months after the week than prior to attending the week (see table 5.1).

**Table 5.1: Mean scores for Stigma (4 items) before (Time 1) and two months after (Time 2) attending the Holistic Therapy Week**

Time 1 Sum of Stigma	6.9143	35	2.59379	.43843
Time 2 Sum of Stigma	8.1714	35	3.56029	.60180

The therapy week provided a de-stigmatising environment for PwP and their family or carers to meet together socially with understanding and without embarrassment. It may be that the contrast between this and lived reality once away from Blackpool led to expressions of relative perceived stigma. Some support for this notion was provided by one of the nurses, who explained the social embarrassment of living with Parkinson's:

*'Mealtimes ... you know ... many people have said they don't go out for a meal anymore ...they don't want to embarrass others ...and when they're dribbling and things, if they're around others that are doing the same, they don't feel like everybody's watching ...' (Lines 223-239)*

On the other hand, there may be nothing to explain. When the original questionnaire data were scrutinised, it appears that on ly one person's scores changed substantially over time, and it is possible that the statistical result can be explained by this one person's experience.

#### **General Feedback on the week**

The interviews detailed again and again how the week *'makes you feel valued'* (Peter, line 5) and how some people *'would like to go for a fortnight'* (Maud, line 49). In addition to the research reported above, some general feedback was gathered during the week about

**how the facility used in the 2006 Holistic Therapy Programme might be improved. These included:**

- 1. Access to lifts. This needs to be improved so that wheelchairs can be used easily.**
- 2. Lecture Sessions. More forward details of these could be circulated so that PwP and their families could make better informed decisions as to what to attend and where, on any specific day.**
- 3. Use of hotel foyer. This was a natural meeting and greeting point that all hotel guests had to cross to go into meals. In future years all events should be plotted onto a large board or poster and left in full view of people for the entire week.**
- 4. Room usage. A number of PwP reported missing the 'quiet rooms' provided by the Hotel management in previous years. At least two such areas should be designated as 'quiet' areas in the future.**
- 5. Research activity. With the original booking forms that go out to branches prior to booking hotels for the Therapy Week, there should be a box to tick that says 'I agree to participate in any research activities taking place during the Week'. Clearly anyone whose health impairs such participation will not be excluded from attending future Weeks, but those who agree should be prioritised.**
- 6. Recognising that those attending the therapy week comprise a relatively large group of PwP and partners, research activity should be well-planned to take advantage of this situation. Calls for research specific to the venue could be issued by the PD Society (UK) through its publications.**
- 7. Speech and language therapists should be encouraged to develop expertise with PwP by advertising the need for students' attendance at the Week.**

- 8. The massage and beauty therapists who worked so assiduously in 2006 should be allowed to accept gratuities/tips in the future. Their services were very much appreciated and those benefiting from their skills should be able to show their appreciation.**

#### **5.4: Comments on the evaluation method**

**The evaluation was a mixed method evaluation that sought to collect information about people's experiences of the therapy week as well as measure any lasting effects of changes in quality of life over time. These changes were to be measured by the PDQ39 prior to the week, immediately following the week and one month afterwards. In the event no useable data were collected immediately after the week.**

**All measures that could possibly be used to encourage the return of the second batch of PDQs were taken. When all the PwP were checking out of the hotel, they were specifically reminded that they would need to complete and return the questionnaires fully, so that evaluation of the week could be continued and ultimately completed. Although everyone agreed to comply, the most likely explanation for the failure to secure returned questionnaires, was tiredness of the participants. Half way through the week, one participant in the Carer's Forum noted how tired people were getting:**

***'There's a lot of tired Parkinson's sufferers now, because (for) three days they've been really trying to hit the button (Pauline, Lines 314-315).***

**Possibly the effort involved in 'hitting the button' took its toll in the weeks immediately following Blackpool, and interfered with the collective resolve to help with this research.**



**What was perhaps most surprising was that the final stage of the questionnaire distribution was almost as successful as the first with a 75% return rate, although because some of these questionnaires had missing data, they were excluded in the statistical analysis.**

**The audit of activities, initially appeared to be straightforward. In the event, the audit proved very difficult indeed. With the undertaking of the evaluation came a commitment to carry out a minimum of 46 interviews over just four days (30 with PwP, eight with therapists and a further eight with family members or carers of PwP). Because no-one could be interviewed until they had participated in some of the activities, these interviews could not be started until Tuesday morning. At the same time as the interviews were being recorded, the audit figures needed to be tallied. Names of those attending sessions were not taken which made it impossible to match up PDQ data with attendance at particular sessions, thus rendering the questionnaire analyses less useful than intended.**

**As we have seen above, the statistical analyses of the PDQ39 failed to pick up on any measurable increase in Quality of Life due to attending the Holistic Therapy Programme two months after attending. The only statistically significant finding from the questionnaires was that there was an increase in feelings relating to perceived 'stigma' after two months, and this finding could be explained through one individual's experience. In the final test, but, when scrutinised, this seemed to relate to a single individual only. For most of the questionnaire analyses, sample sizes were small. Once all the questionnaires with missing values or ambiguities had been removed, there were between 31 and 35 left for the different types of analysis. More importantly, statistical analyses were undertaken on the whole group results and not confined to those**

who attended particular events, thus making meaning interpretation difficult.

### **5.3: People with Parkinson's and their wellbeing or quality of life**

Although the well-validated PDQ39 Quality of Life measure was used to help evaluate the Therapy Week, the statistical results previously presented in this report suggest that this might not have been the best instrument to utilise in this way. There were minimal changes in reported following the Week's therapeutic interventions, but the interview data strongly contradicted that. This dissonance alone leads to consideration that the measure was unsuitable for such a study. Because researchers have discovered that QoL is as much about attitude as it is about health states (Bowling, Gabriel, Dykes, Dowding, Evans, Fleissig, Banister & Sutton (2003), future investigations, or evaluations such as this study, should carefully deliberate about methodological choices.

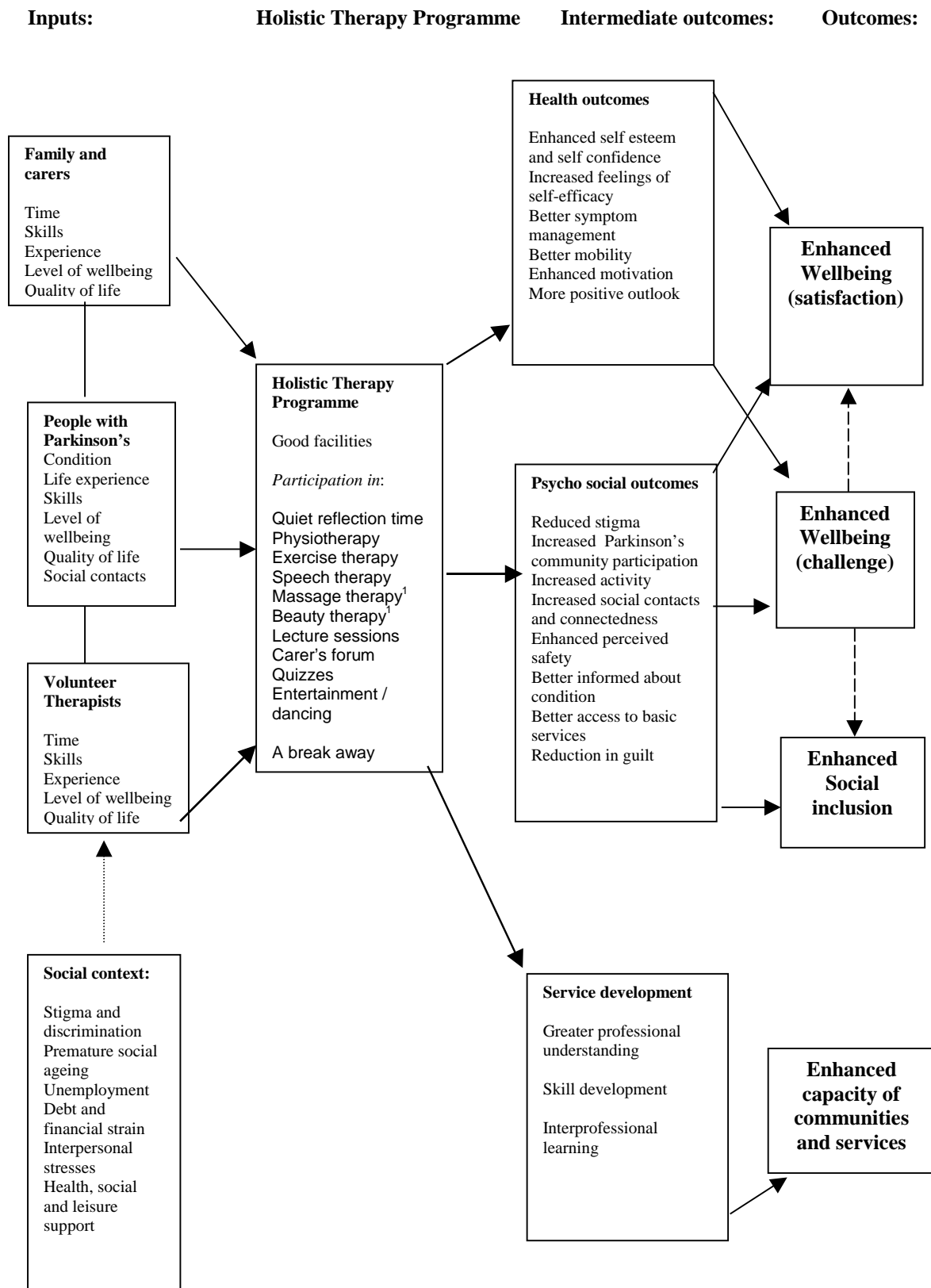
However, the evaluation did have an impact on people's wellbeing.

The most comprehensible way to see how well-being and Parkinson's were linked when evaluated in this study is to consider Figure 5.1, which diagrammatically represents the role of the therapy week in contributing to wellbeing, through improvements in health and psycho social factors.

There was no doubt of the value that PwP *and* their families placed on the social interaction the therapy week offered. Then again, the opportunity to be research active and possibly 'make a difference' for others with PD also seemed to be a strong motivator for those who volunteered to be interviewed. There were constant reminders that the week represented a dynamic process which was circular in its actions and outcomes, or as Joshua said:

***`You interchange ideas, thoughts, and treatments,  
and everything ... you get different perspectives  
...You learn from them and they learn from you'  
(Joshua, Lines 30-32).***

**Figure 5.1. The impact of the Holistic Therapy Programme on the health and social inclusion of People with Parkinson's and thus to their wellbeing and social inclusion**



But at all times during this circular process, there was the one the dominant recurring theme. This was the need for research that would benefit PwP today and not just in the future. where PwP . Perhaps this was articulated most vividly by Suzie in the second Carer's Forum:

*'And I would trek the Namibian desert to raise £3,000 towards that – as an able-bodied person .... I'm more than happy to raise money that will benefit People with Parkinson's NOW. I'm not interested in raising money for research - there's other people that have to do that - I'm more happy to raise money so people can have it now ...'* (Lines 205-209)

Suzie's comments were supported by a show of hands from 18 other carers. Whilst the medical research moving ever nearer discovery of a cure is seen as important, participants also recognised the urgency of broader research to illuminate the promotion and support of wellbeing and quality of life. Jennie, whose husband was a young-onset PwP put it thus:

*"Everybody's talking about finding a cure, doing gene research and maybe we will have eliminated it for our grandchildren ... which is great, yes, we don't like to think of them having Parkinson's, but it doesn't change our lives at all. We've got another 20 years at least"* (Jennie, Lines 382-387).

Calls for further research were not separated from resources targeted at therapy and psycho-social support. There were especially strong views expressed about the need for the PD Society to use its assets for:

*'more PD Nurses, more community support workers, more specialist physios, one in each region'* (Anna, lines 164-165),

and to enable the kind of support and benefits experienced during the week:

***'I know money is needed for research and management of the Society, because those things are desperately important, but perhaps selfishly, I want help NOW. TODAY for me, my husband and all the baggage that comes with us ...' (Anna, Lines 168-171).***

**The last words on the benefits of the Holistic Therapy Programme rest with Joseph, as did the first:**

***'[I am able to] relax. I find this situation so beneficial in that, just for a week, you are back to normality' (Joseph Lines 128-129).***

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## **APPENDIX I: Interview Schedule**

These questions are to find out how you have experienced the holistic therapies programme week. They are all loosely connected to wellbeing and include questions about your reactions to specific activities as well as to the week in general. The questions will tap into your personal feelings of satisfaction as well as to the social side of the activities on offer. Any ideas for how such a week might be improved will be welcome. Each area of question topics will start at a general level and become more specific.

### **Background**

- Previous experiences of Blackpool weeks
- Duration of PD
- General experience of PD and its impact on wellbeing

### **Motivation**

- Reasons for attending
- How choices were made about what activities and therapies to try

### **Specific Therapies**

- Effect of different therapies and activities
  - What these were and why chosen
- Which therapies or activities before this one
  - Does experience of a therapy influence experience of subsequent ones— how?
- How they made you feel
- What differences were made to physical condition
- What challenges did they present
- What could have made the experience a better one
- Overall impact on wellbeing

### **Social activities**

- Which ones attended and why
- Level of participation and contacts revived or newly made
- What could have made the experience a better one
- Overall impact on wellbeing

### **General facilities**

- Positive? Negative?
- What could have made the experience a better one
- Overall impact on wellbeing

### **Overall evaluation**

- Best things? Worst things?

Recommendations for improvement  
Ideas for what you will do differently when you get home

**For volunteer therapists and/family members: as above, plus**

Specific activities

What benefits they afforded

How they may be improved for the future

Which enhance feelings of satisfaction and which of challenge

General balance between social interaction and individual therapies and activities.

## **Appendix II: Introductory letters for PwP**

### **LETTER ONE:**

**Dear                    ,**

**As a researcher at the Manchester Metropolitan University (MMU) currently working in the field of Parkinson's Disease (PD), and a person with a positive family history for Parkinson's, I have been funded by the PD Society (UK) to assess the impact of the Therapy Week you will be attending next week in Blackpool. One aspect of my assessment involves People with Parkinson's (PwP) completing the attached 'Quality of Life' questionnaire. The same questionnaire will need to be completed again at the end of the Therapy Week, and a third questionnaire will be posted to your home address in the following weeks. This will give three separate scores for 'quality of life' which will be compared, statistically, to assess the impact of the Week on your well-being. When you arrive at Blackpool, please hand the completed forms either to me (Dr Diane Loggenberg), to Mr Alan Pulford (Vice-Chair of the Blackpool Action Group), or place your completed questionnaires in the box on the information desk.**

**The second strand of my investigation requires that I talk fact-to-face with a selected few of you who might like to express your views as to the impact of the Therapy Week. Our conversations will be taped at the time and transcribed later (on return to university) so that the content and your comments can be analysed. I will be looking for 'commonality of content' in the transcripts, and generally evaluating how participation in the Week was experienced.**

**I would like to emphasise that your participation in this project is really appreciated. By contributing to the research, you will be helping lay people understand how the various therapies on offer at the Week impact on Parkinson's and how/if they are valued by PwP. The data collected in Blackpool will provide an evidence base for future funding decisions the PD Society has to make. All information**

received will be treated as highly sensitive and neither your name nor your identity will ever be revealed.

If you have any queries, I can be contacted at the University on 0161-247-2597 or by e-mail at: [D.Loggenberg@mmu.ac.uk](mailto:D.Loggenberg@mmu.ac.uk).

Yours with thanks,

Dr Diane Loggenberg (Researcher)

LETTER TWO:

January 2007

Happy New Year to You,

And let's hope that this is a breakthrough' year for People with Parkinson's. A year when Parkinson's becomes better understood; a year that marks a greater awareness of the challenges associated with the disorder; and a year when all those involved with PD recognise that *the people* are, and always will be, more important than *the Parkinson's*.

For this reason, I am contacting you again to complete the attached PDQ40. I wonder if you remember that when you took part in the Blackpool Holistic therapy week, you agreed to complete a number of these questionnaires? This is the final one for your attention and, once this is returned here to the university, I can analyse the impact of the Holistic Week, and compile my Report for the Parkinson's Disease Society. I have included a stamped addressed envelope for your convenience. If you have any queries, please do not hesitate to phone me on 0161 247 2597.

Yours gratefully,

**Diane Loggenberg (Dr)**  
**Carolyn Kagan (Prof) Parkinson's Disease Research Team**

**APPENDIX III: About You and PDQ39**  
**ABOUT YOU**

Names and addresses are for contact purposes only and will never to be revealed. Before you begin we would like you to answer a few general questions about yourself by circling the correct answer or by filling in the space provided.

1. Name .....

2. Address .....

.....

.....

..... Postcode .....

Tel No: .....

3. What is your gender? MALE / FEMALE

4. What is your date of birth? -----/-----/-----  
(day/month/year)

5. What is the highest education you have received?

None at all

Primary School

Secondary School

Tertiary

6. What is your marital status? Single Separated  
Married Divorced  
Living as married Widowed

7. Do you have any serious illness other than your Parkinson's disease?

.....

.....

8. How old were you when you were diagnosed with Parkinson's disease?

9. Do you currently take any drugs to combat depression? YES / NO

10. If you answered yes to the above, which anti-depressant medication are you receiving and what is the daily dosage?

.....

11. Has any other member of your family had a diagnosis of Parkinson's Disease? This could be a living or deceased relative. If the answer is yes, who is the person and how are you related?

.....

.....

## The Parkinson's Disease Questionnaire : PDQ - 40

This questionnaire was commissioned and funded by the Parkinson's Disease Society of the United Kingdom to 'attempt(ed) to systematically evaluate the impact of the illness ... from the individual's perspective'.

**Please tick the box which best describes how often during the last three months have you had trouble with each of the items listed below.**

Response Options -      1 = Never  
                                      2 = A little of the time  
                                      3 = Some of the time  
                                      4 = Most of the time  
                                      5 = All of the time

**Example:** If you try and conceal your Parkinson's disease from everyone except your close family members, then your response to ITEM 4 would be a tick in the box headed 'most of the time'.

Now respond to all the items listed below remembering that the question is **'How often during the last three months have you had ?**

	Never	A little of	Some of	Most of	All of
the		the time	the time	the time	the time
time					

	ITEM	1	2	3	4	5
1.	Difficulty with leisure activities					
2.	Difficulty washing yourself					
3.	Had difficulty getting around public places					
4.	Felt you had to conceal your PD					
5.	Had problems with close relationships					
6.	Unexpectedly fallen asleep during the day					
7.	Had difficulty with speech					
8.	Had painful muscle cramps or spasms					
9.	Had difficulty looking after your home					
10.	Had difficulty dressing yourself					
11.	Felt isolated and lonely					
12.	Avoided eating or drinking in public					
13.	Not had support from spouse or partner					

14.	Had problems with concentration					
15.	Felt unable to communicate properly					
16.	Frightened or worried about falling in public					
17.	Had difficulty carrying bags of shopping					
18.	Had problems doing up buttons or laces					
19.	Felt weepy or tearful					
20.	Felt embarrassed by having PD					
21.	Not had support from friends or family					
22.	Felt your memory was bad					
23.	Felt ignored by people					
24.	Felt unpleasantly hot or cold					
25.	Had problems walking half a mile					
26.	Had problems writing clearly					
27.	Felt angry or bitter					
28.	Felt worried by others reaction to you					
29.	Had distressing dreams or hallucinations					
30.	Had problems walking 100 yards					
31.	Had difficulty cutting up food					
32.	Been confined to the house more than liked					
33.	Had problems getting around the house					
34.	Felt depressed					
35.	Had difficulty holding a drink					
36.	Felt worried about the future					
37.	Needed to be accompanied when out					
38.	Had aches and pains					
39.	Felt anxious					
40.	Had difficulty with your sex life					

## **Appendix IV: Consent Forms**

**I hereby consent to be involved in research being carried out by Dr Diane Loggenberg and Prof Carolyn Kagan. I understand that the project entitled "An Evaluation of the Holistic Therapies Programme for People with Parkinson's" (held in Blackpool, 2006), has been funded by the Parkinson's Disease Society (GB), and is sited within the Department of Psychology at the Manchester Metropolitan University. I can contact either of the researchers involved in the study on 0161 247 2000 or by e-mail<sup>11</sup>.**

**I understand that I will complete three quality of life questionnaires (distributed before, during, and after the Therapy Week) and, according to my own preferences, may also be interviewed about my Parkinson's Disease.**

**I understand that my participation is completely voluntary, and that I am free to withdraw from the study at any time I choose.**

**I understand that this project is not expected to involve any risks or harm, and I also understand that the findings from of the research may be published for government agencies, funding bodies, or scientific groups, but that my name will not be associated in any way with the published results.**

**I understand that, should I volunteer for interview, the tapes that ensue will be my personal property, that all interview transcripts will be forwarded to me for approval before being analysed and that I have the right to veto their use at any point, even after all research work has been completed.**

**Finally, it has been made perfectly clear to me that there are no 'right' or 'wrong' answers in this study, that MY views are the most important views and that I am free to discuss my life with as much or as little detail as I choose.**

**Signature of Researcher  
Parkinson's Disease**

**Signature of Person with  
Parkinson's Disease**

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Date .....

## **APPENDIX V: Information on Research**

### **What is the research about?**

Over the years people who have attended the Blackpool therapy week have claimed it has positive benefits. However, this has not been researched in any formal way. This year it is proposed to find out what people think and feel about the therapy week and how it affects their wellbeing. The overall aim of the study is to carry out an exploratory evaluation of the holistic therapy programme from the perspectives of those people with Parkinson's attending, volunteer therapists and family members. Specifically the study aims to:

1. gain information about participants' reported positive and negative experiences of different activities on offer during the week in terms of their wellbeing (in terms of satisfaction and pleasure as well as personal development and growth);
2. assess the extent to which gains in terms of quality of life or 'well-being' (using the PDQ39) of participating in the week last over time; and
3. provide information that will lead to the enhancement of future weeks as well as the viability of holistic therapy programmes for use elsewhere.

### **How will the research be carried out?**

There will be two stages to the research. One stage will be to ask all those people with Parkinson's to complete a Quality of Life questionnaire before the week, at the end of the week and again one month later. You may know this questionnaire – it is the PDQ 39. This will give us important information about how you were affected by the week, but most importantly, whether any positive (or negative) effects lasted once you returned home. Although we ask for your name on the questionnaire, this is only so we can match up the scores from the different times you complete them. Once the data have been put into the computer, all means of identifying you will be destroyed. If you return the questionnaire we will assume you have consented to participate in the research.

The other stage will be to undertake interviews (each lasting about 20 minutes) with people who have attended the different activities during the week. We aim to interview in total 30 people with Parkinson's, 12 family members and 12 volunteer therapists. We will be asking about your experiences of the different activities, including therapy, activity and social activities. All interviews will be anonymous and you (or those you talk about)

will not be identified in any way. The interviews will be tape recorded so that they can then be written out. The interviews will be analysed and common themes across different groups of people attending the week will be identified, as well as issues that some people raise but that others do not. If you are invited, and agree to take part, you will be asked to sign a consent form to indicate that you have been informed about the nature of the research, and that you have given your consent freely. You are being given this information sheet in advance so that you have time to think about being involved and to ask any questions about the research.

### **What will be done with the results of the research?**

A report will be written for the Parkinson's Disease Society that includes quotes from what people have said, but all these will be anonymous. In addition, changes to the measured quality of life over time will be summarised. The two sources of information will be combined to draw out lessons about what has worked well with the week and what not so well, in order for recommendations to be made regarding any similar programmes in the future. A summary of the research will be sent to all those who attended the holistic therapies programme.

### **How might I be involved?**

All those people with Parkinson's Disease who are planning to attend the holistic therapies programme will be invited to complete the questionnaire before leaving for Blackpool, at the end of the week and again one month later. Completion of the questionnaire is entirely voluntary and you may withdraw your involvement at any stage.

During the week, people attending different activities may be invited to take part in an interview. Not everyone will be asked – our plan is to get as broad a range of people as possible. Your involvement will be entirely voluntary and you may decide to withdraw your involvement at any time. In addition some of the volunteer therapists and family members will also be asked to take part in an interview on a voluntary basis. Again, we will try and get a broad section of those attending to take part.

### **Are there any risks to my participating in the research?**

There are no risks to your participating. All involvement is voluntary and will not affect access to any of the therapies or activities. All information will be confidential and you will not be identified in any way.

### **Who is conducting the research?**

The research will be carried out by researchers from the Research Institute for Health and Social Change at Manchester Metropolitan University. (You can find out more information about the Institute from the web-site [www.rihsc.mmu.ac.uk](http://www.rihsc.mmu.ac.uk) ) A team of researchers and members of local PDS groups have developed the research and will continue to steer it as it progresses. Diane Loggenberg will undertake the research. She has worked with people with Parkinson's and has contributed to previous therapy weeks in Blackpool. Diane will be undertaking the interviews and collecting the

questionnaire data. The data will be entered onto computers by independent data processors and by Diane. Diane will analyse the data and write the report. A steering group, which will include a senior researcher and a person with Parkinson's will provide guidance to Diane throughout the project.

**How do I find out more?**

Diane can be contacted at [d.loggenberg@mmu.ac.uk](mailto:d.loggenberg@mmu.ac.uk) or by phone 0161 247 2597. If you would like to talk to the senior researcher, Professor Carolyn Kagan can be contacted at [c.kagan@mmu.ac.uk](mailto:c.kagan@mmu.ac.uk) or by phone at 0161 247 2563.