PARKINSON'S UK CHANGE ATTITUDES. FIND A CURE. JOIN US.

Information and support worker service user survey 2012

Contents

Summary

Background

- The information and support workers' team provides a one to one service to people affected by Parkinson's across the UK in a number of ways, including face to face at home or in the community - by phone, email and letter.

ForOver 6 weeks in October and November 2012 we sent out a total of 1269 service user surveys to gather feedback from clients about the service to ensure quality and inform service development.

- We received a total of 590 completed surveys, increasing the sample size by 93% compared to 2011.
- The response rate was 46%. 80% responded by post and 19% via the web survey.0.7% requested a telephone interview.

Survey respondents

- The majority of respondents (69%) were aged over 65.
- 4% of respondents came from black and ethnic minorities.
- 64% of respondents had Parkinson's themselves and 21% were carers, friends or family members. 14% indicated that they were responding as a couple, being both a person with Parkinson's and a carer.
- 52% of clients had had contact with their ISW between 2 – 5 times.
- Compared with last year, this year's sample included a higher percentage of clients who had been diagnosed four or more years ago.
- Of those who did respond, 59% (311) were members of Parkinson's UK and 50% (264) were members of a Parkinson's local group. 190 respondents were members of both.

Contacting and accessing the service

- The majority (36%) of respondents found out about the service via their Parkinson's nurse. 19% found out via a local group or branch and 16% reached the ISW service via other Parkinson's UK services.
- The main reason stated for contacting the ISW service was for a information, help, advice and support, ranging from the broad to the very specific. Help with financial and benefit issues and form filling was also frequently mentioned. A significant number said they did not contact the ISW service; instead they were contacted by the ISW. Few people mentioned emotional support as a reason for contacting the service.
- 95% of clients responding said they had 'no problems' contacting the ISW, while 4% had 'a few problems'.
- The majority (75%) of people had face to face contact, while 69% had contact by telephone, 18% by email and 9% by letter.
- There is a slight increase in the time it takes to deliver a home visit compared with 2011, however of those who needed a home visit the majority (88%) received this within 2

weeks. 12% said that it took more than two weeks to receive a home visit, but only 1% said that they did not receive a home visit within the time they needed. This indicates that the longer time period between first contact and home visit was suitable for most people.

Integrated information and support service

- As well as using the ISW service many clients also used other Parkinson's UK services.
  - 79% said their ISW told them about the local support groups, 65% said they have used these groups.
  - 65% of respondents said their ISW told them about the helpline and 34% said they used the helpline.
  - 50% said they had been told about the website and 47% reported to have used the website.
  - 7% did not use any other Parkinson's UK's services.
  - 16% (35 individuals) used three or more of the other services available.

Quality of service

- 91% of clients responding to the survey received the information they needed from their ISW. 8% had not received this yet as their ISW was still supporting them.
- 100% of clients felt the ISW was friendly and polite.
- 100% of clients felt fairly treated.
- 99% would recommend the service to others.
- 81% rated the service as excellent and 16% as good. 99% rated it satisfactory or above.

Impact

- 89% strongly agreed or slightly agreed with the statement *"The information I received from the Parkinson's UK information support service has made a positive difference to my life as a person affected by Parkinson's".*

Areas of life the respondent felt there had been a positive difference:

  - 66% said confidence
  - 64% said benefits and other financial issues
  - 47% said they were better able to manage living with Parkinson's
  - 46% said emotional wellbeing
  - Other areas included access to health services; mobility; social support; carer's issues; care and social care; help with complaints procedures; respite care; housing; holidays and employment.

Conclusion

- The ISW service continues to be extremely well appreciated. 81% of clients rate the service as excellent compared to 74% in 2011. 99% would recommend the service to someone else, compared with 98% in 2011.
- Although there was an increase in the time it took to deliver a home visit compared with 2011,

only 1% said that they did not receive a home visit within the time they needed, compared with 3% in 2011. This is a fantastic result, particularly because monitoring data points to a significant increase in the number of referrals. This suggests that ISWs are monitoring their workload and making the best use of home visits and phone calls to allow them to respond to need appropriately.

- 89% said they strongly agreed or slightly agreed with the statement *"The information I received from the Parkinson's UK information support service has made a positive difference to my life as a person affected by Parkinson's".* As well as appreciating the practical information and support clients receive, a significant number experienced a positive benefit to their confidence and emotional wellbeing. This is particularly interesting since this was not identified as a reason for contacting the service; it assists us in recognising the real values of the service and the areas that are most important to our clients. It also helps us demonstrate the real impact of the service, which will aid us in promoting the service to professionals and to people affected by Parkinson's.
- Comments further support the value placed on the information and support received, whether it's face to face, by phone or email. Clients report feeling they do not have to *'face Parkinson's alone'.*
- For an overview of ISW service development suggestions see page 26.

Background

Information and support workers (ISWs) form part of Parkinson's wider information and support services. The ISW team provides a one to one service to people affected by Parkinson's across the UK in a range of ways including face to face - at home or in the community -by phone, email and letter.

During October and November 2012 we undertook our annual survey of a sample of users of the ISW service. This survey aimed to gather service user feedback on the service to ensure quality and, combined with the service's monitoring data, inform further development. The information gathered is useful for the charity as a whole and it provides a valuable source of case studies.

Survey respondents

This year the surveys were sent to a total of 1269 service users; an 89% increase on last year. We received a total of 590 completed surveys, increasing the sample size by 93% compared with 2011. This success has been largely due to the commitment of the ISWs and excellent interdepartmental working. Extending the sample time by two weeks may also have uplifted response.

The response rate was 46%, which is identical to 2011. The majority (80%) responded by post, but the number of people responding via a web-based survey more than doubled since last year (19% in 2012 compared to 7% in 2011). This year, for the first time, we offered phone interviews for those who had difficulty completing the paper or online survey. 0.7% (4 people) used this option.

A number of surveys had missing data where some questions had not been answered. For the purpose of analysis, this missing data is excluded from the figures reported below.

Person living with Parkinson's

Table 1 shows that the majority (64%) of respondents had Parkinson's themselves and 21% were carers, friends or family members. 14% indicated they filled in the form as a couple comprising a person with Parkinson's and a carer.

Table 1: Type of respondents

I am:	Total	%
a person with Parkinson’s	348	64%
a carer/friend/family member	114	21%
both - filled in as couple	75	14%
other	5	1%
totals	542	100%

(11% did not answer this question)

Age

Table 2 shows the age group of those responding. The largest proportion was aged over 65 (69%), while 29% were between the ages of 45 and 64. 2% were under the age of 44.

Table 2: Age group of respondents

Age group	Total	%
24 and under	0	0%
25-44	11	2%
45-64	153	29%
65-84	343	65%
>84	23	4%
totals	529	100%

(10% of respondents did not answer this question)

Time since diagnosis

Table 3 below shows the length of time since diagnosis.
This year the majority (38%) of our sample had been diagnosed between 4-10 years ago.

Table 3: Time since diagnosis

Time since diagnosis	total	%
less than 2 years	146	30%
2-3 years	87	18%
4-10 years	184	38%
11-20 years	64	13%
>20 years	5	1%
totals	485	100%

(18% did not answer this question)

The ISW service is supporting people at varying stages of their Parkinson’s journey and clients are likely to be experiencing a range of issues which need support.

Length of support

For the first time this year we asked about the number of contacts service users had had with their ISW. In table 4 we can see that the majority (52%) of those who answered this question had had two to five contacts with their ISW. 16% had had contact once and 31% had had contact six times or more. This indicates that clients present with a range of support need of varying complexity.

Table 4: Number of contacts between respondent and ISW

Number of contacts with ISW	total	%
once	91	16%
2-5 times	295	52%
6-10 times	98	17%
> 10 times	80	14%
totals	564	100%

(4% did not answer this question.)

Looking at table 5 we can see that the majority (32%) of clients had their first contact with the ISW service more than one year ago, 26% had their first contact within the last month and 2% within the last week.

Table 5: Time since respondents' first contact with ISW

First contact with ISW took place	total	%
in the last week	11	2%
within the last month	149	26%
less than 3 months ago	110	19%
less than 1 year ago	118	21%
more than 1 year ago	183	32%
total answered	571	100%

(3% did not answer this question)

Ethnicity

This question was not answered by 7% of the survey respondents. Of those responding, the majority (95%) defined themselves as white English/Welsh/Scottish/Northern Irish/British and 1% as white Irish, while 4% were from black and minority ethnic communities, compared to 3% in 2011. It is worth noting that the monitoring data shows that 5% of all clients using the service are from black and minority ethnic communities.

Geographic area

Participants were asked to select where they lived in the UK from a list of areas. Table 6 shows that respondents are fairly evenly spread across the UK, with the majority coming from the north west of England (13%) and the smallest sample of people coming from Northern Ireland (3%).

Table 6: Location of respondents

The Parkinson’s UK regions respondents are from			
Eastern England	6%	South of England	12%
East Midlands	6%	South East of England	9%
London	7%	South West of England	7%
North east of England	8%	Wales	5%
North west of England	13%	West Midlands	7%
Northern Ireland	3%	Yorkshire and Humber	8%
Scotland	8%		

(7% did not answer this question.)

Membership

This year we asked about Parkinson’s membership for the first time. 11% did not answer this question. Of those who did respond, 59% (311) were members of Parkinson’s UK and 50% (264) were members of a Parkinson’s local group. 221 respondents (42%) were members of both.

Contacting the ISW

How did you find out about the ISW service?

Table 7 shows how those responding found out about the ISW service. Some people indicated more than one source of the information, therefore the total is more than 100%.

Table 7: How respondents found out about the service

How respondents found out about the ISW service	2012 Total	2012 %	2011 %
Parkinson's nurse	209	36%	51%
Parkinson's UK branch or group	108	19%	16%
Parkinson’s clinics	66	11%	n/a
Consultant	55	9%	10%
Parkinson's UK website	42	7%	8%
Friends/relatives	39	7%	7%
GP	32	5%	4%
Parkinson's UK helpline	24	4%	3%
Parkinson's UK publications	12	2%	4%
Social Services	18	3%	3%
Parkinson's UK information event	18	3%	3%
Other health care professionals	9	2%	n/a
Other, including other voluntary organisations	27	5%	1%

Although Parkinson’s nurses are still the most common way for people to find out about the ISW service, there is a fall in the percentage of people who found out about the service via their nurse in 2012. This may be due to the fact that we introduced ‘Parkinson’s clinics’ as an option in this year, which is where Parkinson’s nurses are often based.

In line with the previous survey, Parkinson’s UK branches and groups were the next most common way for people to have found the ISW, with 19% reaching ISWs this way.

A total of 16% of respondents reached the ISW via other Parkinson’s UK services (excluding branches and groups). These were: the website (7%); our publications (2%); the helpline (4%); or an information event (3%).

Some people commented on the fact that they had not found out about the ISW service where they would have hoped to, particularly at point of diagnosis:

> *"After my initial diagnosis, I was given no information about help or support available… I do think help should be given immediately after diagnosis, as one can feel isolation and shock, needing help and advice."*
>
> *"Not being told at the hospital or doctors about Parkinson's support service. I felt so alone."*

This indicates a need for clear and targeted publicity of the information and support service, promoting the role to key professionals and ensuring that our own Parkinson's UK materials are clear about routes of access to information and support.

During the autumn of 2012, as part of Parkinson's UK's work in 'reaching everyone', specifically designed promotion packs went on display at GP practices across the UK. As part of this work the regional and country teams engaged with consultants throughout 2013 with the aim of increasing the number of people who receive information about Parkinson's UK at point of diagnosis.

Reasons for contacting the ISW service

When asked why they initially contacted the ISW service, the majority (154 of the 484 who answered this question) said they were looking for information, help, advice and/or support. This included information and advice about Parkinson's and living with the condition; information about what the ISW service can offer and what other help is available; help with navigating the health system; information on medication and continuing care; and very specific support around for example sourcing waterproof sheets and pads. Comments included:

> *"For help, advice and guidance on continuing healthcare, which was invaluable."*
>
> *"For support and guidance. Find out about local groups and services."*
>
> *"I wanted assistance in finding more about Parkinson's and how I might manage in the long term."*

A significant number of respondents (130 of the 484 who answered this question) mention support with financial issues (including benefits) and help with filling in forms as reasons for contacting the service:

> *“To help fill out benefits form and to see what help I was entitled to.”*
>
> *“To help me get some support to try and help with care for my husband also to help me fill out my career's assessment forms.”*
>
> *“To get assistance in completion of Disability Living Allowance Form”*

A significant number of respondents (70) reported contact with the ISW took place on advice of another professional such as a GP, specialist nurse or consultant. A number of these reported the ISWs initiating contact by phoning them:

> *“They contacted us! My husband had fallen through the benefits net.”*
>
> *“I did not. She rang to make an appointment to visit us at home because we had just moved to the area and had my first visit at the Clinic.”*
>
> *“She contacted me soon after the diagnosis was confirmed by the consultant neurologist.”*

For many this worked well and they benefited greatly fromthe service. However there are some who received a visit on recommendation of another professional when they didn’t feel they needed one.

Conducting a follow up phone call with a client who commented in her survey *“They (the ISW) contacted me via Parkinson’s nurse”* uncovered that her nurse, who was retiring, had referred her to the ISW service. The client consented to this because “*professionals tend to know these things”.* She subsequently received an ISW visit. However, the client commented that she didn’t need help, particularly with finances which was what the ISW was focussed on, and that she would have preferred just a phone call.

This highlights the need to educate other professionals about the ISW service as well as the necessity to screen referrals from other professionals for suitability and need.

A few respondents (eight) indicated they contacted the ISW service because they needed emotional support:

> *“I needed to speak to someone as my husband has just recently got into a nursing home and I am very upset.”*

> *“I was very depressed.”*

It is interesting to note that emotional support scored highly in ‘areas in which people felt they received support from their ISW’ as well as ‘areas where the service made a positive difference’. For more about this see page 20.

Problems making contact

As shown in the table 8 below, 95% of clients responding said they had ‘no problems’ contacting the ISW, while 4% had ‘a few problems’.

Table 8: Problems contacting the ISWs

Experiencing problems making contact with ISW	total	%
no problems	546	95.5%
few problems	24	4.2%
many problems	2	0.3%
totals	572	100%

(3% d id not answer this question)

As with last year’s results, some did not seem to know who the information and support worker was, indicating a need for clarity around roles and ensuring that referrers are clear about reasons for referral and that the client wants contact:

> *“Not knowingly had any contact with ISW.”*

Often, however, clients may have many different health and social care professionals involved in their care and can sometimes get confused about the role of each worker. It is therefore essential that ISWs explain their role to clients and make it clear what support can be offered.

Of those who experiencedproblems, the main issue was the ISW not being readily available on the phone:

> *“I could not get hold of my local ISW initially by telephone and I don’t like leaving voice messages but I found email successful.”*

> *“Difficulty making contact by phone to actually talk to a living person when having problems dealing with my husband regarding his unfounded worries for advice.”*

> *“Being on ‘annual leave’ or ‘out of hours’ ok but not if an immediate response is needed.”*

In the last situation, a follow up call to the client indicated he was not aware of the Parkinson's UK helpline and the provision of nurse call backs. He felt knowing about this would have been beneficial for him, particularly when he needed advice about medication.

We need to ensure we publicise the information and support service in an integrated way so that people affected by Parkinson's are aware of the various routes to information and support. Again, a clear explanation to clients about roles is important. Alternative Parkinson's UK services and other contacts should also be provided and explained.

Accessing information from ISWs

Table 9 shows in what way the respondents had contact with their ISW. A number of people had contact with their ISW in more than one way; therefore the total is more than 100%.

The majority of people had face to face contact (75%). 69% had contact by telephone, 18% by email and 9% by letter.

Table 9: Type of contact with the ISW

Contact with ISW	Total	%
face to face meeting	432	75%
by telephone	398	69%
by email	105	18%
by letter	49	9%

(2% did not answer this question)

Table 10 shows whether respondents felt they needed a home visit. 83% indicated needing a home visit, which is a drop of 13% compared to last year, when 96% indicated needing a home visit.

Table 10: Respondents needing a home visit

Needing a home visit	2012 total	2012 %	2011 %
yes	457	83%	96%
no	93	17%	4%
total answered	550	100%	100%

(7% did not answer this question)

It is worth noting that 16% of respondents indicated that so far they had only had contact with their ISW once. This might mean they have not had the opportunity to meet the ISW face to face yet, as often the first contact takes place by telephone. This would account for the discrepancy between indicating needing a home visit and having received one.

Not everyone wants or needs a home visit. Some respondents noted that face to face contact is not always necessary:

> *"…I received face to face meeting, a phone call would have been sufficient. It would have been better if I had been asked if I needed a visit as I would have preferred just a phone call."*
>
> *"I received face to face meeting, a phone call would have been sufficient."*

It's important that we offer a person centred service; one that is responsive to individual personal preferences, needs and values. This includes recognising that the information and support provided by phone is often valued as much as a home visits and that it is important to give people a clear choice in how to access the service.

Table 11 shows how soon the home visit was received for those responding to this question.

Table 11: Waiting time for home visit

How soon the home visit was made	2012 Total	2012 %	2011 %
within one week	194	41%	49%
Wwithin two weeks	221	47%	40%
longer	55	12%	11%
Ttotals	470	100%	100%

(20% did not answer this question)

There is a slight increase in the time it takes to deliver a home visit compared with 2011, however of those who needed a home visit the majority (88%)

received this within two weeks. 12% said that it took more than two weeks to receive a home visit. Only 1% said that they did not receive a home visit within the time they needed. This is an improvement on last year's figures, when 3% did not receive a home visit within the time they needed. This indicates that a slightly longer time period between first contact and home visit was suitable for most of these people. This is a great result particularly because ISW monitoring data points to a significant increase in the number of new clients.

Integrated information and support

The ISW service is part of Parkinson's UK's wider information and support service, which includes the helpline, telephone peer support service, the local groups and branches as well as the website and the online discussion forum.

Table 12 looks at what other Parkinson's UK services the ISW has told the clients about (that they can remember), as well as what other services the client has used. As some clients have used or been told about more than one service the total adds up to more than 100%.

The majority of respondents (79%) said that their ISW told them about the local support groups. 65% said they have used these groups.

65% of respondents said their ISW told them about the helpline and 34% said they used the helpline.

50% said they had been told about the website and 47% reported to have used the website.

16% (35 individuals) used three or more other services available and 7% did not use any of these.

It is worth bearing in mind that some of the clients who indicated having used other services might have done this before receiving an ISW service. That's because 35% of respondents found their way to the ISW service via another Parkinson's UK service, including those mentioned below.

As there are many ways in which individuals can interact with Parkinson's UK there is the real possibility that this happens 'organically' and that it could include having contact with multiple sources of help and information at any one time. To find out more about how clients interact with the whole organisation we would need to conduct a customer journey mapping exercise.

Table 12: Respondents aware of and using other Parkinson's UK services

Other Parkinson's UK services	My ISW told me about total		I have used	
	total	%	total	%
helpline	313	65%	107	34%
website	246	50%	150	47%
online discussion forum	86	18%	29	9%
telephone peer support service	144	29%	25	8%
local support groups	386	79%	208	65%
none of these	6	1%	22	7%
total answered	491		319	

Where respondents commented on other Parkinson's UK services they were complimentary:

> *"For the first time I contacted the Parkinson's staff it was through this help line, I was not well. I have been in a low mood and depressed. I was feeling useless, I willed the helpline and staff there has been perfect. They talked me into contacting my local support worker. Who came to my house and talked to me about my needs and really been grateful to me."*
>
> *'My confidence has grown due to becoming a member of Parkinson's UK and by reading all the quarterly newsletters and magazines, which I find very informative. (....) By joining the Newcastle branch of PUK, I have made many new friends (...)'*
>
> *'When I rang the Parkinson's help line they were very good. Also receiving the quarterly magazine is very informative, helps with the emotional parts.'*

Quality of the ISW service

A number of questions in the survey related to the quality of the information and support provided by the ISW., Table 13 provides more detail. The responses were overwhelmingly positive and really indicate the significant value placed on support from an ISW.

Table 13 shows 91% of those responding received the information they needed, while 8% answered 'not yet' as the ISW was still supporting them.

Only two people said the information was not useful. In both cases clients reported that they did not instigate contact with the ISW but were approached by them, very likely on recommendation of another professional. One of these clients had only had email contact with the ISW once in the week before completing the survey.

Table 13:Quality of service

Summary of responses	
received the information needed (8% answered not yet - the ISW is still supporting me)	91%
understood the information received	99%
ISW was friendly and polite	99.6%
felt they were treated fairly	99.6%
would recommend ISW service to someone else	99%
would rate the service as excellent or good	97%
would rate the service satisfactory or above	100%

99% of respondents understood the information received. 2% would have liked to have received the information in another format; this includes another language as well as receiving the information in spoken form due to visual impairment.

Everyone responding (100%) said the service they received was friendly and polite and that they were treated fairly.

99% of those responding said they would recommend the ISW service to someone else. 1% was not sure.

The survey asked how clients would rate the ISW service overall. 97% rated it as either ‘excellent’ or ‘good’, with the remaining 3% rating the service as ‘satisfactory’. Breaking this down further we see in table 14 that there has been a positive shift from ‘good’ to ‘excellent’ compared with 2011.

Table 14: Respondents rating the service

How would you rate the service?		
	excellent	**good**
2012	81%	16%
2011	74%	23%

Two people rated the service as poor. A follow up call with one of these clients indicated he was confused as to what the ISW service was. He had not understood that the GP and the Parkinson's nurse were not part of the ISW service; his dissatisfaction was mainly with them.

Comments made on the form reinforce how positive the majority of people were about the support received:

> *"I could not ask for more. I was in need of help myself as well as my husband. My ISW I cannot speak highly enough of. She is an asset to your society."*
>
> *"My experience of the service has been first class."*
>
> *"I have been grateful for the advice received and found it very beneficial to have such easy access to information when required."*
>
> *"As newly diagnosed, I had no idea where to turn. I have found all contact with ISW service to be very helpful. All have been polite and friendly also supportive. I do not know what I would have done without them all."*
>
> *"Before Parkinson's appeared I was a senior manager and I do not need my hand held but did need a push in the right direction. The ISW was brilliant at picking up what I wanted and provided it in a style that suited me perfectly. It was left at my request that I would crack on and get in touch if I needed further help. Her help saved me a great deal of wasted time and stress. I was very impressed by her and her command of the job."*

Impact

89% said they strongly agreed or slightly agreed with the statement *"The information I received from the Parkinson's UK information support service has made a positive difference to my life as a person affected by Parkinson's"*. (73% strongly agree,16% slightly agreed) 10% said that they neither agreed nor disagreed with this statement and 1% (six people) strongly disagreed.

Of the six people who strongly disagreed four had only had contact with their ISW once. People had different reasons for not agreeing with the statement ranging from not understanding that the ISW service does not encompass the Parkinson's nurse and GP to needing, and not receiving, information in another language.

Table 15 shows that the number of people strongly agreeing with this statement increases over time. One contributing factor could be that the impact of some actions takes longer to be felt, for instance accessing other services or getting the results of a benefit claim.

Table 15:Positive impact on respondents' lives

"The information I received from the Parkinson's UK information support service has made a positive difference to my life as a person affected by Parkinson's".	**Time since first contac with ISW**				
	last week	**within 1 month**	**less than 3 months ago**	**less than 1 year ago**	**more than 1 year ago**
strongly agree	40%	60%	73%	79%	82%
slightly agree	30%	24%	16%	13%	12%
neither agree nor disagree	20%	14%	11%	8%	5%
slightly disagree	0%	0%	0%	0%	0%
strongly disagree	10%	1%	1%	0%	1%
total number of respondents	10	139	113	116	169

Again this highlights the need for integrating Parkinson's UK's support offer and communicating clearly what the offer is. We also need to ensure ISWs have clear guidance about accessing translated materials and translation services.

Table 15 shows the areas of life where the respondent felt there had been a positive difference. Many people experienced a positive difference in more than one area; therefore the total is more than 100%.
The majority (66%) of people felt more confident as a result of receiving the service.

Table 16: Areas of positive impact

In what area(s) of life has there been a positive difference?	
confidence – i.e. being more informed about Parkinson’s and support available	66%
benefits and other financial issues	64%
better able to manage living with Parkinson’s	47%
emotional wellbeing	46%
access to health services	30%
mobility	29%
social support - i.e. access to local support group or a befriending scheme	28%
carers’ issues	21%
care / social care	12%
help with complaints procedures	7%
respite care	6%
housing	6%
holiday	3%
employment	3%

Further comments relating to the top eight areas of positive benefit:

Confidence
Comments from clients explain that gaining information about the condition and the health system, and knowing what trustworthy help is available have a big impact on their confidence. Increased confidence will help people live fuller lives and can be just as important as having practical help:

> *“I feel more confident knowing that help and support is available for me and my wife. We both feel at ease talking to someone who had a great personality and understood the effect Parkinson's has on both patient and carer. (...) My wife is pleased that there is also support available for carers.”*
>
> *“Our only contact about help and support, that gives us confidence, to carry on, with life.”*
>
> *“Without the help received by (my ISW), I would still be in my room more than not. Her help has been invaluable and although many things can't be sorted out, it has given me the confidence to do things and meet people. In fact, stand on my own two feet knowing she is there should I need her.”*

Comments highlighted how valuable people found the ISW service particularly when newly diagnosed:

> **“***When I was first told of my condition, it was very hard to take in. My local ISW was there for me in the early stages and still is. Lots of things have changed in my life as a result! But I know that I can contact my ISW and she will visit me A.S.A.P.”*
>
> *“I was newly diagnosed with Parkinson's and had virtually no knowledge. Talking to my ISW (...) has helped me realise that I can still live quite a normal life.”*

Benefits and other financial issues

Receiving the right benefits can have a big impact on clients’ quality of life. The ISW service has helped clients with these both in terms of assisting clients to complete benefit forms as well as supporting clients to access, and make the most of, other, more suitable, sources of help:

> *“The benefit I have obtained has enabled me to make other arrangements in being able to travel/ do shopping i.e. use taxis more when shopping and be so dependent on others.”*
>
> *(...) I was successful in my claim for benefits which helps with the additional costs, i.e. I have joined a gym, go tea dancing (which the consultant is very pleased with) go to hydrotherapy, and thinking about trying Pilates. All these activities are to try and keep me mobile and fit, but without the financial help I wouldn't be able to afford them. The Blue Badge has been a godsend.”*
>
> *“It was suggested that a person with DWP should come to the house and fill out the application form. This was done 3 years ago for daytime AA (...).”*

Better able to manage living with Parkinson’s

Comments suggest that clients reporting a beneficial impact of the service on their ability to cope with Parkinson’s contribute this to a range of factors including gaining information, having practical problems solved and receiving emotional support:

> *“I now feel better able to cope with having Parkinson's knowing that support is available. Within a week I have been supplied with special equipment to help with my mobility problems. My quality of life has been much improved.”*

> *"Giving me emotional support means I am better able to live with Parkinson's with confidence."*

Emotional wellbeing

Few clients contacted the ISW service to access emotional support. However, 35% indicated having received information and support in this area and 46% of people felt that the ISW service had made a positive difference to their emotional wellbeing, highlighting this as an added benefit. This indicates that people initially contacting the service for information, practical advice and support, often also experience a beneficial impact on their emotional wellbeing.

The additional comments made by clients really show the value placed on having someone to talk to who understands Parkinson's and who can provide information, reassurance and support:

> *"Talking face to face with someone who understands all problems you incur with Parkinson's, has helped me come to terms with it and also has helped meeting other sufferers with whom we chat, discuss and socialise together."*
>
> *"I was on a real low feeling suicidal at times, but being able to talk to someone who cares and understands my issues was the best tonic I could possible have. The support worker helped sort out my benefits and helped restore my self confidence. Helped me to pick myself up and to realise there was still a lot that I could do although I have to stop work; there was still a purpose for living. She made me smile again."*
>
> *"Having a chat with someone sympathetic to my problems has given me a more positive attitude. (...)."*
>
> *"That someone who I can talk to who understands has been a great benefit when it has come as a complete shock to me."*

Access to health services

It can be confusing to clients finding their way around the health (and social care) system, particularly when first diagnosed. Comments suggest that having the support from an ISW helps with finding the way and ironing out any issues that may arise:

> *"Access to a falls prevention clinic and physio. (...)*
> *Liaising with local NHS services where problems have occurred."*

> *“Of greatest significance have been the introduction to the Parkinson's Clinic at Edgware Community Hospital.”*

Mobility

Mobility is a big issue with Parkinson’s and is crucial for maintaining independence. Mobility can be benefited in a number of ways as comments suggest:

> *“General advice on living with Parkinson's. Advice and help with getting physio visits and access to equipment when carer had mobility problems also.”*
>
> *“I would not have been able to fill in the form for the blue badge without the help of the support worker, and she told me about getting other equipment for my home.”*
>
> *“I have joined the exercise class and found this has helped my mobility. I attend the local meetings held once a month. I have had handles fitted in the house and gardens.”*

Social support

People living with Parkinson’s can benefit greatly from meeting with others affected by the condition. Comments suggest the help of ISWs in signposting and giving support and encouragement is beneficial:

> *“I was encouraged to go to functions held by the local support group. I was unsure about this as I didn't want to see people with PD in the advanced stages. Once I decided to go, I found everyone friendly and supportive.”*
>
> *“It has been of great benefit to meet with other Parkinson's patients to discuss symptoms, medication and generally living with Parkinson's.”*

Carers’ issues

The ISW service also provides support and information for carers. 21% were carers, family members or friends and 14% of those completing the survey did this as a couple. Comments indicate that the ISW service is beneficial to both:

> *“The support I have received had helped me to cope with my husband's condition and I know that I can contact my ISW for help and advice when I need it.”*

> *“Our contact helped involve Dad in practical courses (mobility, speech therapy) and to seek out a carer to ease the workload on family. Also to have my parents' flat assessed over mobility issues.”*

Suggestions for improvements

The survey asked for suggestions for improvement. The main suggestion was to ensure the service is well publicised - particularly via the GP or consultants for those newly diagnosed:

> *“Little information is available at the initial point of diagnosis. An info pack ought to be issued at the hospital at the moment the diagnosis is given.”*

> *“Maybe the ISW service could be publicised more so that earlier contact could be may by newly diagnosed people if required. It's those early months that are the hardest and often require greater support and when you are hungry for information but a bit scared to look for fear of what you may find!!”*

> *“Hospital or G.P... should automatically put patient in touch with ISW.”*

A number of clients indicated they would have rather received the information by phone as they did not need a home visit:

> *“It would have been better if I had been asked if I needed a visit as I would have preferred just a phone call.”*

Some commented on the need for a befriending service:

> *“Personal home visit befriending the real requirement for those, whether PD sufferers or carers, totally home bound.”*

Some commented they would like to know what the ISW could help with so they can make a more informed choice about when to call on them:

> *“Rather than telephone out of the blue and expect me to bare my soul asking 'how I am' perhaps she might list what she can offer and I respond when I have time to reflect.”*

> *“Although I knew of the support workers I didn't realise at first that they could help with filling in forms. Is there a list of things that support*

> *workers do? There are probably other ways a support worker could help us but I don't always think to ask."*

One client remarked on the ISW job title:

> *"Quite frankly, I don't like the title ISW. It is cumbersome and awkward. To the public, it is a meaningless abbreviation and when told what it stands for, there is still a blank look on one's face. The word 'information' is ambiguous - what kind of information. (...)"*

Conclusion

How the survey can inform ISW service development

The results of the 2012 service user survey are again extremely positive, and clearly show the value that clients place on the ISW service. The survey has highlighted some areas for development of the service:

A number of clients were confused as to who the ISW was and what other services they could access. Others directly requested a clear explanation of ISWs and other Parkinson's UK services , so they could make an informed choice as to whose help they enlist.

- In line with a person centred way of working, we need to check with the client how and what type of support they need. This requires communicating clearly what the ISW service can offer as well as being able to signpost to the right organisations and other services at Parkinson's UK to provide the client with a range of options.
- We need to ensure that we publicise and communicate the information and support service in an integrated way so that clients accessing the ISW service are aware of the information and support available as well as how to access them. As part of this we're developing an online client record system which will allow us to give clients a more integrated journey through our services and enable other services, like the helpline, to support clients more effectively.
- We're looking to develop toolkits to support ISW service delivery, including tools to help assess the needs of clients, referral checklists and clear pathways for referrals within Parkinson's UK as well as partner and other organisations.
- We plan to develop partnerships with other organisations to help improve client's choice (as well as free up ISW time) and to maximise the impact of our work.

- We'rewriting a new set of ISW guidelines and policies to help support ISW practice and give clear guidance about how to proceed in key areas of work.

A number of clients experienced problems contacting their ISW and reported the ISWs not being available at all time as an issue.

- Again this highlights the need to manage the clients' expectations and communicate clearly how the ISW service works and signpost them to the most appropriate service. For instance if a client is looking for an immediate response they can call the helpline.
- It also emphasises the need to educate other professionals so they are clear about the service provided when referring.

Clients who found out about the service and received support when newly diagnosed expressed great appreciation for this. Others who did not find out about the service at point of diagnosis, highlighted that they felt the lack of this.

- There is a need for clear and targeted publicity of the information and support service, promoting the role to key professionals and ensuring that Parkinson's UK materials clearly show routes of access to information and support. Our 'reaching everyone' programme of work is addressing this issue and has already involved a campaign to display posters and leaflets in GP practices across the UK. This work will continue in 2013. The regional and country plans for 2013 also include work to target consultants with a view of getting information about Parkinson's UK to newly diagnosed individuals.

Some clients were referred by other professionals (such as Parkinson's nurses) when they did not require the ISW service's help.

- We need to educate referring professionals to ensure they understand the ISW service's remit, which would contribute to more appropriate referrals. We also need to ensure professionals are aware of the whole range of information and support we offer at Parkinson's UK so they can signpost to the most appropriate service.
- There is a need for more effective screening of referrals for appropriateness and need in line with a person centred approach

Ensuring quality

The ISW service continues to be extremely well appreciated. 81% of clients rate the service as excellent compared to 74% in 2011. 99% would recommend the service to someone else, compared with 98% in 2011.

Although there was an increase in the time it took to deliver a home visit compared with 2011, only 1% said that they did not receive a home visit within the time they needed, compared with 3% in 2011. This is a fantastic result, particularly because monitoring data points to a significant increase in the number of referrals. This suggests that ISWs are monitoring their workload and making the best use of home visits and phone calls to allow them to respond to need appropriately.

89% said they strongly agreed or slightly agreed with the statement *"The information I received from the Parkinson's UK information support service has made a positive difference to my life as a person affected by Parkinson's".* As well as appreciating the practical information and support clients receive, a significant number experienced a positive benefit on their confidence and emotional wellbeing. This is particularly interesting since this was not identified as a reason for contacting the service; it assists us in recognising the real values of the service and the areas that are most important to our clients. It also enables us to demonstrate the real impact of the service, which will help us promote the service to professionals and to people affected by Parkinson’s.

Comments further support the value placed on the information and support received, whether it’s face to face, by phone or email. Clients report feeling they do not have to ‘face Parkinson’s alone’.

We intend to review the way we collect feedback from service users to ensure we are evaluating the service appropriately and measure outcomes and impact.