

West Berkshire LINK and West Berkshire Neurological Alliance

Joint Survey on Incontinence – Feb 2013

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Executive Summary

Background

Following a successful focus group conducted by the West Berkshire Neurological Alliance (WBNA) at Padworth in March 2012 (see Appendix 1) the LINK offered to facilitate a wider community survey of services for people with incontinence across the Western part of Berkshire.

Methodology

A draft questionnaire was developed by the WBNA in March 2012 and was sent out to member organisations and other stakeholders for comment.

After making some amendments a final version (see Appendix 2) was approved and 200 sets of questionnaires complete with reply paid return envelopes were prepared. We expected that it would be difficult to recruit people to the survey despite guaranteeing anonymity and so it turned out. We did manage to distribute all 200 through a variety of conduits including :-

WBNA member organisations

The West Berkshire incontinence service – Teresa Dunbar

17 other local voluntary organisations with an implied interest

The returned questionnaires were analysed and recorded by the LINK administration officer, Man Liu Clarke, on Excel spreadsheets.

The report was prepared by Tony Lloyd, the West Berkshire LINK chair, with advice from the WBNA and others.

A draft copy of the report was sent to the West Berkshire Incontinence service and an extract of their response is included in Appendices 5 and 6

Results

Out of 200 questionnaires distributed only 27 (14%) were returned. This was a **very** disappointing response rate.

Most of the statistics that follow are based on low numbers, so the findings should be regarded as indicating trends, flagging up possible concerns and indicating where priorities might lie for further data gathering.

Findings

- 1) There is a wide variety of experience of incontinence services and products .
- 2) A significant proportion of patients and their carers were having problems in coping with incontinence.
- 3) The continence adviser and the continence clinic are highly regarded for their understanding of the condition and for the help that they provide. This is in stark contrast to GPs and consultants who are not generally so highly rated.
- 4) Many patients with incontinence are unaware of the incontinence service.
- 5) Those that do access the NHS incontinence service give it good ratings and there are few criticisms of NHS continence products apart from single examples of excessive bureaucracy and availability.
- 6) The voluntary sector was not rated highly for the support provided to patients with incontinence problems.

Recommendations

- 1) The commissioning of incontinence should be investigated further and reviewed leading to actions that will:
 - a) improve the availability and quality of information about incontinence and what can be done for those in need
 - b) improve continence training / knowledge of GPs and community nurses
 - c) improve and standardise the continence care pathway leading to increased referrals to local specialist Continence Advisory Services
 - d) reduce the misery of many local people living with incontinence
- 2) There is a clear need for GPs and consultants to recognise that many patients do not feel that they understand their incontinence problems or provide adequate help in dealing with them. It is recommended that they recognise these shortcomings and try to remedy them.
- 3) It is recommended that referrals to the incontinence service for a comprehensive incontinence assessment should be encouraged as should specific incontinence training for front line staff at surgeries.
- 4) CCG commissioners should ensure that there is adequate capacity in the continence services and review referral rates to identify anomalies.
- 5) Though not specifically derived from this survey but rather from the focus group (Appendix 1 – recommendation 6), it is recommended that the policy on the

provision of free continence care products to those in need should be made available in the public domain and should be reviewed as to content, appropriateness, relationships between quality and clinical value, consistency of current compliance and possible improvement..

6) It is recommended that relevant voluntary groups should bear in mind their low ratings for understanding and helpfulness and work with professionals to try to identify potential improvements.

Tony Lloyd (West Berkshire LINK)

John Holt (West Berkshire Neurological Alliance)

Feb 2013

Notes

The West Berkshire LINK is an independent Local Involvement Network. We have a statutory duty to gather the views of patients and the public about the health and social care services that they experience and to report those to commissioners and providers of those services. We are also required to make recommendations for the improvement of those services.

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Detailed Report

Demographics

The responses came from across the West of Berkshire [Reading 7, Wokingham 7, West Berkshire 10. 3 responses did not state the local authority area]

Two thirds of the respondents were women (17 out of 27) and there was a wide age range though 16 of the 26 who responded were older than 65.

A third of respondents (7 of 23) had no mobility impairment, another third (7 out of 23) used a walking aid and another third (9 out of 23) were wheelchair users.

12 of the 27 filled in the form themselves but the majority were completed by someone else, usually the spouse.

Type of incontinence

We asked people about the nature of their incontinence and received the following response.

	Not at all	Sometimes	Quite a lot	Most or all of the time
How bladder incontinence affects you?	12%	19%	19%	50%
How bowel incontinence affects you?	25%	25%	17%	33%

Likely cause of incontinence

81 % (21 of 26) advised us that their incontinence derived from a specific condition (Stroke, Parkinson's, dementia etc.) (See Appendix 3 for details) There was only one respondent who attributed it to child birth and this aspect of incontinence needs further investigation. (see Appendix 4 re Stress Urinary Incontinence and developments at the Royal Berkshire Hospital.)

How well people are coping with incontinence.

We asked how well people were coping with their incontinence and, out of 26,

- 7 (27%) said "not at all",
- 4 (15%) said "a little" ,
- 7 (27%) said "some of the time well" and
- 8 (31%) said "almost all of the time"

11 out of the 26 (42%) were therefore having regular or significant problems in coping with 69% coping only some of the time, a little or not at all

Help and advice

We asked people “Do you believe you have all the information, help and advice you need to manage your incontinence as well as you ever could?”

It was evident from the answers that a few people had been pleased with the help that they had received

- *Very good help from district nurse*
- *The help has been very good*
- *Yes, information / advice is good*
- *Because I employ my own PAs directly via LA DP&ILF, I have control over my bowel and bladder management that would not be possible via nurses.*
- *I am happy with the advice, help and products I receive to help me with my incontinence, and keep it under control and manageable.*

Others were more critical

- *As my husband's carer, I have to do all the managing. I have had to seek out information, help and advice. Nothing was suggested to me. Everything was a case of trial and error.*
- *Mainly night time incontinence. It has been very difficult to find advice and help - social services are not able to help, district nurse has given only limited help.*
- *No. There is quite a lot of help for bladder incontinence but the only advice for bowel incontinence is to eat more fibre and improve the diet. I don't know when I need to go or if I have been.*
- *I have had this problem since birth (there was a weakness on both sides of the family) and have attended various hospitals since the age of about 5 including The Bladder Hospitals in London (4 near The Strand) and wish they could be more widely advertised even some doctors don't know of them.*
- *I found out about such things as waterproof mattress and waterproof duvet covers on the net. Leaflets explaining all these type of products should be available.*
- *Would like help with knowledge, ideas for dealing with dementia and incontinence. I am struggling. The products have to be bought are expensive, bed pads, washable slippers, carpet cleaning materials, bath aids that allow*

for appropriate washing.

- *My wife followed up articles/magazine ads anything that might improve my life. Professionals tend to only answer/deal with issues you raise instead of if this happens what we could do. You need to know the questions to ask in order to get an answer. If we ask too many questions it gets expensive as items cost money.*
- *Colon and Colitis specialist nurses and consultants be informed of the work of the NHS Colitis service and they, in turn, inform those diagnosed with Colon's / Colitis. If I had known that pads were available for night time use then both myself and my wife would have slept a little better during my last several flare-up. I still don't know if I am entitled to them or from where I get them.*

It is clear that a number of people face or have faced significant problems in getting adequate information about the condition.

Impact of incontinence

We asked people about the impact that incontinence had on their lives and received the following responses :-

	Very negative	Negative	No impact	Positive	Very positive
General physical health	4 (19%)	4 (19%)	13(62%)	0	0
Condition of my skin	3 (13%)	6 (26%)	12 (52%)	2 (9%)	0
Bladder infections	2 (10%)	7 (33%)	8 (38%)	3 (14%)	1 (5%)
My psychological outlook	1 (4%)	9 (38%)	9 (38%)	4 (17%)	1 (4%)
Leading an active life	3 (12%)	7 (28%)	8 (32%)	6 (24%)	1 (4%)
My quality of life	2 (8%)	10 (42%)	8 (33%)	3 (13%)	1 (4%)
Personal relationships	1 (5%)	7 (32%)	13 (59%)	0	1 (5%)
My self-esteem	1 (4%)	10 (43%)	8 (35%)	2 (9%)	2 (9%)
Being fulfilled	1 (5%)	6 (29%)	12 (57%)	1 (5%)	1 (5%)

The main points from this table are

- a) **The adverse impact on the individual's health** with 38% indicating an adverse affect on general health, 39% indicating an adverse affect on their shin condition and 43% reporting a negative impact on bladder infections.
- b) **The adverse affect on peoples mental health** with 42% reporting adverse psychological impacts, 37% reporting an adverse impact on personal relationships and 47% reporting lowered self esteem.
- c) **The adverse affect on peoples quality of life** with 40% reporting an adverse impact on their ability to lead an active life, 50% reporting a negative impact on their quality of life and 34% not feeling that they are fulfilled.

Needs

We asked people how easy it was to find things that they might need and they responded as follows :-

	Easy	Fairly easy	Not very easy	Difficult
Timely and suitable information	4 (15%)	11 (42%)	7 (27%)	4 (15%)
Timely and suitable advice	4 (15%)	11 (42%)	6 (23%)	5 (19%)
Effective management options	3 (12%)	8 (32%)	9 (36%)	5 (20%)
Effective products that suit me	4 (15%)	14 (52%)	3 (11%)	6 (22%)
Effective support	6 (23%)	11 (42%)	4 (15%)	5 (19%)
Ways to adapt to change	3 (12%)	8 (32%)	7 (28%)	7 (28%)

The table once again indicates a wide variation in experience and perhaps the most striking result is that more than half of the respondents think that it s not easy to find effective management options.

A typical comment is :-

Mostly incontinence information etc has come from trial and error solutions building up my experience of how to deal with situations as when and after they arise. Was given no information on aids to deal with results of incontinence from NHS sources.

Unsurprisingly, with management options not initially easy too to find, 56% reported difficulties adapting to change. The responses would seem to indicate that people affected by incontinence are likely to experience change and may have ongoing needs to be in touch with up to date advice.

Quality of Services

We then asked for people's views on the services available for incontinence by asking whether they agreed with certain statements. They replied as follows:-

	Strongly Agree	Agree	No view	Disagree	Strongly disagree	Not applicable
The NHS continence service is easy to contact	6 (24%)	8 (32%)	3 (12%)	5 (20%)	2 (8%)	1 (4%)
The NHS continence service is well run	5 (20%)	8 (32%)	7 (28%)	1 (4%)	1 (4%)	3 (12%)
The NHS continence service is well resourced	3 (12%)	5 (20%)	10 (40%)	4 (16%)	1 (4%)	2 (8%)
I get all my continence care products from the NHS	7 (27%)	7 (27%)	2 (8%)	2 (8%)	7 (27%)	1 (4%)
The NHS products I use are the right quality for me	3 (12%)	15 (58%)	2 (8%)	1 (4%)	1 (4%)	4 (15%)
It is easy to order or reorder continence care products from the NHS	6 (23%)	10 (38%)	4 (15%)	1 (4%)	2 (8%)	3 (12%)
I have enough space to store my continence care products	3 (12%)	12 (48%)	4 (16%)	4 (16%)	0	2 (8%)
I am given appropriate continence care prevention information from the NHS	2 (8%)	9 (38%)	5 (21%)	3 (13%)	4 (17%)	1 (4%)

This table indicates that clients generally regard the continence service as being well run (only 2 of 25 disagreed) though 7 out of 25 thought that it was difficult to contact and 5 out of 25 thought it was not well resourced.

Some respondents were not even aware of the NHS continence service

- *I didn't know that the NHS continence service existed until I was contacted by a third body about taking part in this survey.*

- *I have never tried to contact NHS Continence Service. Maybe I should.*
- *What care products are available from NHS?*
- *Was not aware of the NHS continence service*

There was a criticism about the bureaucracy

- *It now takes 2 weeks receive products as an application has to be made by provider for a prescription. The prescription returned before dispatch.*

and another about the NHS products

- *The products the NHS supplies are impossible to use. I am disabled and simply can't hold the pad in the net because I need one hand to hold on to something.*

And yet another about the availability of some continence products

- *I get the pads - 2 types supplied which is greatly appreciated but getting waterproof pants is very difficult. Boots are the only firm who keep them in stock. Various chemists can order them from a catalogue but they are very much more expensive and it isn't always very clear what they are like. The same applies to ones available on the internet. Most chemists and supermarkets now keep the pants with a pad as part of the garment but those are much more heavy to wear, not so discrete and not so easy to change if your need to when out shopping etc. I always carry a spare pad with me in case I need it and can go into a public toilet and change it and be dry and comfortable in a few minutes.*
- *I would like more advice as to where to obtain a neen / pericalm device.*

There is clearly some dissatisfaction regarding the need to pay for continence products and this raises questions about the assessment process that is currently adopted.

The products themselves seem to be satisfactory (only 2 of 26 disagree) and relatively easy to reorder (3 out of 26 disagree) and store (4 out of 25 disagree)

Only 11 out of 24 felt that they had been given appropriate information on prevention and this is a cause for concern

Understanding and helpfulness

We went on to ask about the extent to which healthcare professionals understood peoples incontinence needs and were helpful.

The responses are set out below

	Not applicable	Not at all	Small Extent	Quite well	Very well
GP	4 (17%)	4 (17%)	7 (29%)	4 (17%)	5 (21%)
District/Community nurses	7 (29%)	2 (8%)	4 (17%)	4 (17%)	7 (29%)
Continence advisor	7 (32%)	3 (14%)	0	1 (5%)	11 (50%)
Specialist Continence clinic	11 (46%)	3 (13%)	0	3 (13%)	7 (29%)
Urology or bladder specialist	13 (57%)	4 (17%)	2 (9%)	3 (13%)	1 (4%)
Other hospital staff	11 (46%)	5 (21%)	2 (8%)	5 (21%)	1 (4%)
Physiotherapist	15 (65%)	4 (17%)	0	3 (13%)	1 (4%)
Psychological support worker	15 (65%)	4 (17%)	2 (9%)	2 (9%)	0
Occupational Therapist	16 (70%)	4 (17%)	1 (4%)	2 (9%)	0
Social Services Care Manager	14 (61%)	5 (22%)	1 (4%)	3 (13%)	0
Voluntary sector	14 (61%)	3 (13%)	4 (17%)	2 (9%)	0

It is difficult to interpret this table due to the number of “Not applicable” responses. The table below restates the data by excluding those responding ‘not applicable’

	Number Rated	Not at all	Small Extent	Quite well	Very well
GP	20	4 (20%)	7 (35%)	4 (20%)	5 (25%)
District/Community nurses	17	2 (28%)	4 (23%)	4 (23%)	7 (41%)
Continence advisor	15	3 (20%)	0	1 (7%)	11 (73%)
Specialist Continence clinic	13	3 (23%)	0	3 (23%)	7 (54%)
Urology or bladder specialist	10	4 (40%)	2 (20%)	3 (30%)	1 (10%)
Other hospital staff	13	5 (38%)	2 (15%)	5 (38%)	1 (8%)
Physiotherapist	8	4 (50%)	0	3 (37%)	1 (12%)
Psychological support worker	8	4 (50%)	2 (25%)	2 (25%)	0

Occupational Therapist	7	4 (57%)	1 (14%)	2 (28%)	0
Social Services Care Manager	9	5 (55%)	1 (11%)	3 (33%)	0
Voluntary sector	9	3 (33%)	4 (44%)	2 (22%)	0

Perhaps the most striking line in these tables is the comparatively poor rating of GPs and district nurses in comparison with the continence adviser and the specialist continence clinic though the fact that a significant proportion of respondents chose the “not applicable” option may mean that they were never given specialist advice. Even more of a concern is the fact that the urology or bladder specialists were not thought to be particularly helpful even compared to other hospital staff.

It is disappointing that the voluntary sector fared so badly and the reasons for this need to be better understood. Is it that people are reluctant to seek help or that they regard it as a topic for professionals?

The bulk of comments are from people who are not receiving and in some cases have never received help or advice about incontinence.

- *The only people involved in my care are doctors, district nurses, family and paid carers. I have never been referred to a specialist although I have had bowel incontinence for 18 months and I first approached my GP for help in February 2011.*
- *We are completely on our own. There is no follow up whatsoever. I had to sort out day time pads with help of local chemist. I became very depressed while dealing with my husband's incontinence in 2010. I needed a lot of support then I got none.*
- *Have not had a check up appointment for at least five years.*
- *Other than providing access to NHS pads and a wheelchair with bedpan (which I do not use) there has been no help at all.*
- *Apart from the 'Urology' I have answered 'not applicable' as I have never been contacted by these people and didn't know that I could contact them.*
- *The only person who has given any help has been the district nurse, she is limited to offering only 1 kind of pad.*
- *Once it was discussed, I had more than £23,000 in the bank, I was left to help myself. This meant all health care was left to my husband (who is a retired accountant not medically trained)*

There was one complimentary remark

- *Nurse Jo Balls has been very helpful at Wokingham Hospital*

Conclusions

- 1) There is a wide variety of experience of incontinence services and products by patients.
- 2) A significant proportion of patients and their carers were having significant problems in coping with the condition.
- 3) The continence adviser and the continence clinic are highly regarded for their understanding of the condition and for the help that they provide. This is in stark contrast to GPs and consultants who are not generally so highly rated. There is a clear need for GPs and consultants to recognise these shortcomings and try to remedy them.
- 4) Many patients with incontinence problems are unaware of the incontinence service. It is highly rated and effective. CCG commissioners should ensure that there is adequate capacity and that GPs make more referrals to the specialist service
- 5) Those that do access the NHS incontinence service give it good ratings and there are few criticisms of NHS continence products apart from single examples of excessive bureaucracy and availability.
- 6) The quality and availability of information about products and services for people with incontinence requires improvement.
- 7) Incontinence should be adopted as a specific subject to commission some further local investigations leading to actions that will:
 - a) improve the availability and quality of information about incontinence and what can be done for those in need
 - b) improve the training and knowledge of GPs and community nurses in continence matters
 - c) improve and standardise the continence care pathway leading to increased referrals to local specialist Continence Advisory Services
 - d) improve the performance and perceived approval ratings of urology consultants and general hospital staff
 - e) reduce the misery of a significant proportion of local people living with incontinence
- 8) The voluntary sector were not rated highly for the support provided to patients with incontinence problems. Relevant groups should bear this in mind and work with professionals to try to identify potential improvements

Report for Berkshire West Neuro Local Implementation Team

'Living with incontinence'

Findings from a focus group held at Padworth on 26th March

2012 Executive Summary

Poor control of continence can have a major impact on quality of life, psychological and physical health, personal relationships and self-esteem. Attendees generally had found ways of coping with the challenges of urinary and faecal incontinence, while generally experiencing difficulties in finding timely and suitable information, advice, products and support. The quality of advice from health professionals is variable, sometimes overlooking individual needs. Service delivery could be better coordinated and is inadequately resourced or inappropriately deployed, or both. A service review and upgrade is recommended.

Limitations of this consultation

Neurology conditions are many and diverse and this consultation covered only a limited cross section, with only 9 attendees representing 4 conditions, (one by proxy) a bias as regards age range, (all in the age range 30-70 yrs, noting that the epilepsy incontinence experience started at school age) and a feminine bias, (2M, 7F). There were two carers present. No participants were wheelchair-bound, although one carer looked after a wheelchair-bound doubly incontinent wife and some participants had used wheelchairs previously. Three attendees used walking aids. There was one family support worker present. All attendees were in communication with several others experiencing incontinence. Delegates lived in various locations across Wokingham, Reading and West Berkshire.

Neurological Alliance volunteers led the discussion and two independent sets of notes were taken of the proceedings, (both appended). Care was taken to avoid use of leading questions and attendees determined most of the direction of most of the meeting. There were no service providers, commissioners or statutory sector personnel present. The purpose of the meeting was circulated in advance and attendees were asked to prepare, which all had done. No individual affected by a very rare condition was present, noting that the underlying diagnosis that may have been the primary cause of incontinence was frequently referred to as having some significance as to information needs and management options.

Either individually or collectively, those taking part should not be thought of as being 'representative' or 'typical'. They showed considerably above average personal courage by volunteering to take part and to speak about very intimate matters that most people would find embarrassing to discuss, also displaying high levels of respect towards each other and all commitment to improving services for others.

Analysis of those present:

2 representatives with Parkinson's Disease
2 representatives with Multiple Sclerosis
1 representative with Post Polio syndrome
1 carer of a person with Post polio syndrome
1 carer of a person with MS
2 independent voluntary sector recorders
7 of the 9 attendees were female.
1 person acted as proxy for a young man with epilepsy since childhood.
There were no service managers, commissioners or statutory sector observers

The pre-advised agenda

1. Welcome and introductions
2. Purpose and focus group 'rules'
3. Open discussion on experiences about:
 - obtaining information and advice about incontinence
 - obtaining suitable products and services
 - leading an active and fulfilled life
 - managing when things go wrong
 - adapting to change
 - costs of incontinence
 - what makes a good continence advisory service?
4. Recommendations for the statutory, private and voluntary sectors

The group determined its own priorities for discussion within the above framework.

Themes that emerged

1. Embarrassment barriers surrounding incontinence.
2. Information about incontinence is not readily available.
3. The underlying neurological condition (or other specific diagnosis) is often relevant to determining the best management options. Condition-specific advice exists but is not readily available. Some advice lacks a patient-centred approach.
4. Incontinence affects psychological outlook, is made more difficult by weak physical condition, associates with increased risk of infections and skin problems, all affecting many aspects of leading a normal quality of life at work, with the family and more generally in society.
5. GP knowledge of 'living with incontinence' is sometimes good, sometimes patchy.
6. There appears to be insufficient access to trained continence nurse specialists and a lack of specialist continence clinics.
7. All attendees reported that they have to purchase their continence care products privately, some being partly or mainly supplied with free NHS products, to the extent that the PCT policy is not clear and/or does not appear to be applied consistently.

Recommendations

1. Information about free, professional incontinence services, should be made more readily available, from the CCG, GP practices, Social Services Departments, the Continence Advisory Service, The Urology Team, the voluntary sector and others.
2. Condition-specific advice should be more readily available, wherever this may be appropriate. All advice should be patient-centred, rather than service-driven.
3. Continence Advisory services should be provided in the context of how better management should help to reverse the risk of 'spiral of psychological and physical decline'. It should more often be delivered in a multi-disciplinary context. More preventative activity should be commissioned, to anticipate the changing options that some patients might require and to minimize in particular the risks of psychological decline, social withdrawal, urinary infections and skin problems.
4. GP training in the subject of 'Living with Incontinence' should be improved.
5. The number and availability of Continence Nurse Specialists and Specialist Continence Clinics should be reviewed and improved to meet need. Service delivery could be better coordinated and better resourced or better deployed, or both.
6. The Berkshire West PCT policy on the provision of free continence care products to those in need should be made available in the public domain and then needs to be reviewed as to content, appropriateness, relationships between quality and clinical value, consistency of current compliance and possible improvement.
7. Embarrassment surrounding incontinence need to be lowered, an opportunity for the incoming Clinical Commissioning Groups, GP practices, the Continence Advisory Service, the Community Neuro-rehab Team, the voluntary sector and others.
8. This report should be circulated to local statutory sector commissioners and providers involved with services for people who may be affected by incontinence.
9. The need for a Continence Advisory Service review and upgrade is indicated and the findings of this report should be the basis of a larger survey, to inform that review. Such a survey need not be restricted to the needs of the neurological sector.

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West Berkshire Neurological Alliance
Representing all people in Berkshire West affected by a neurological condition
Registered Charity No: 1081021

**Notes taken by the first independent recorder
Focus Group Meeting — 27th March 2012**

Living with Incontinence

The convenor introduced the discussions by suggesting there seems a mixed bag of information available on living with continence. The following discussion then evolved:

PD Problem of co-ordinating bladder emptying with the 'on/off' situation. When the drugs wear off it is more difficult to cope. This lady has had no incontinence advice — she has learned to manage by trial and error and prepares herself by emptying her bladder at every opportunity.

MS 'People need to ask for help.' The help is probably there but many people feel the problem isn't serious enough to go to the GP about, and feel it is something that they must learn to live with.

MS Botox is sometimes used to help bladder control, also Oxybutinin helps to control and reduce bladder spasm. Some people need to take an antibiotic every night to thwart urinary infections, which in turn can lead to stones forming. The MS can blunt sensations so that you do not always realise that you need to empty your bladder.

Post Polio Needs to wear pads all the time because started leaking from bladder and then bowel. She has no sensation of bowel movement but knows when she needs to pass water, but leaks as well. Has had kidney infections and leakage. Doesn't know if it is a spinal problem or whether the sciatic nerve is pressing on the bowel and bladder or something else. Requested a visit to see a neurologist but had to wait 4 months for an appointment.

MS This person has discovered that a glycerine suppository and laxatose has helped her, but discovered this for herself — no one advised her.

PD Problem of passing water and leaking from the bowel at the same time — when constipated, she doesn't get this bowel leakage. Diet affects the bowel movement. Lactulose makes her too loose. (Fibrogel is meant to ease constipation but can have the reverse effect on some MS patients.)

PD PD drugs tend to make you constipated. Can only pass motions when 'on' drugs. Very difficult when 'off' drugs because you can't get the pants down with one hand, balance problems mean you have to hold on to something at the same time.

One person suggested that a jar of cherries from Waitrose mixed with bran helped with the constipation problems.

Prompt: How do people get their information and help?

From friends, sometimes a GP, a urologist, support groups such as Polio Fellowship.

PP Comments from the PP carer that the specialists don't talk to each other and he would like there to be a case conference involving all the professionals who could discuss all the different problems affecting his wife as a result of this condition. Point made that there are as many people with polio as PD. Constipation and depression are just as important as the motor problems in PD. Complaint that neurologists don't talk to other professionals.

PD Some GPs don't know much about PD and resent the cost of the drugs required.

MS MS carer pointed out that, with advice, certain things can be done by carers at home e.g. bladder washout and catheter care. This can save everyone time, inconvenience, urinary infections and money.

Epilepsy (by proxy) Seizures cause incontinence. If epilepsy can be controlled, then the incontinence can be controlled. If you see the right clinician you get the right treatment, but how do you see the right clinician?

MS Lots of people with MS have bladder problems and these can lead to complications with the kidneys.

Prompt: Cost of incontinence

Time and fatigue. There's also a financial cost — pads can cost a lot of money and the NHS does not always supply them. When does the NHS supply them for free?

The incontinence issue affects people's quality of life, sometimes, to a disproportionate degree. 'I would prefer to have a shorter life of good quality than a long life of poor quality'

Summing up

Incontinence is a hidden condition that can lead to many awkward and embarrassing moments. It is a serious challenge to good relationships between couples. It can be expensive — not only the cost of pads, but also the various 'remedies' that are alleged to help.

Do we have enough continence nurses? Probably not as so few people seem to have seen one.

'It is scary that people do not know enough about incontinence.' Neurology patients have these symptoms which are not seen (especially in younger people) and therefore ignored by the medical profession

A clinic is needed that specialises in Neurology patients and ALL their problems, including incontinence. People should have confidence in discussing this subject.

At the end, the participants said how helpful it was to discuss the issue with others experiencing similar problems.

Notes taken by the second independent recorder Focus Group Meeting — 27th March 2012

A group of people with various neurological conditions met to discuss the problems they face as a result of incontinence caused by their illness.

A very strong message that was expressed repeatedly was the lack of information about what is available or, when the subject is discussed, how appropriate is the information?

Comments from individuals

- Inability to get to the lavatory in time. District nurse suggested a catheter that the patient found unacceptable.
- Loss of sensation. District nurse suggested a suprapubic catheter, which idea was strongly resisted.
- Has had no advice from the medical profession.
- 'No one can cure us', so it was felt that the inclination was for professionals to dismiss the problem.
- Patient with Parkinson's disease said when Levodopa is working she has control but none when the effects from the drug wears off. She has had no advice from the medical profession.

It was suggested that women find the problem easier to discuss than men because of the additional embarrassment men probably feel.

When help has been available, the following were examples;

- Catheter tuition
- Botox injections
- Oxybutynin which reduces bladder spasms.

Leading an active life

- 'Some of us are young'. The medical profession sometimes appears not to care about the quality of life, only the length.

Costs

- 'The underlying disease makes you very tired and it takes longer to deal with problems.'

- 'When continence products are supplied there is not enough to last until the next delivery so one has to buy more.'
- 'Many necessities have to be paid for. They should be free.'
- 'One does not necessarily qualify for financial help.'
- 'One does not always qualify for Disability Living Allowance.'
- The underlying disease is a serious challenge to relationships.
- The disease has caused the husband (carer) to drink more gin!

Problems encountered

- An M/S sufferer has no sensation in her bowels and sometimes defaecates spontaneously.
- A polio survivor had a problem of first leaking from her bladder and then her bowels. She found this very distressing, as she is very fastidious. It lasted about a month but she suddenly became very ill with a bladder infection. She has no sensation in her bowels.
- Suppositories work, but timing is critical so that the resulting bowel movement is at an appropriate time.
- 'My bowels leak without a full bowel movement.'
- 'Parkinson's disease drugs make you constipated. When the effect of the drug has worn off, it is difficult to do anything for oneself.'
- Drugs affect people differently.
- Neurologists and Urologists do not talk to each other. It would benefit patients if they did.
- Drugs cost a lot and doctors worry about their budgets.
- Catheters block. Carers should be allowed to do a bladder washout. In one instance the consultant agreed but the GP refused consent and so the consultant's signature had to be obtained.
- The husband of an incontinent person worries about the problem that would occur if he became ill.
- 'Some of us are young, so there is a large, long-lasting economic burden.'
- Are there enough continence nurses, as some of the group have not seen one?
- The risk of bladder infection can be high and this can make patients very ill.

- Kidney stones can occur when there has been a bladder problem.
- 'Is commissioning going to affect support?'
- 'If you see the best consultant, you are lucky.'

The participants commented that they had found the afternoon's discussion very useful.

Conclusions

There are large numbers of people with neurological disease and there should be more support to help them deal with the inevitable problems that occur.

It is a matter of luck as to whether a patient sees the best consultant, but when that happens much useful support can be gained and life made easier.

When a continence nurse is available she can be very helpful. Unfortunately there are not enough of them.

West Berkshire Neurological Alliance

Representing all people in Berkshire West affected by a neurological condition
Health and Social Care awards winner 2008 'Leadership for Improvement'

2, Clayhill Crescent, Newbury RG14 2NP
01635 33582 johnmholtbsc@aol.com

August 2012

To all local individuals living with or affected by incontinence,

Anonymous survey of local people living with incontinence

We are inviting anyone interested to complete a survey form that we have helped to devise in co-operation with West Berkshire Local Involvement Network (LINK) and others. The survey will take place across West Berkshire, Reading and Wokingham. Everyone who responds will be showing a commitment to improving services for others, so thank you if you decide to take part.

We appreciate that for many people the subject of living with incontinence is about very intimate matters that may be too embarrassing to discuss with other people. For that reason we are not asking for any personal information from anyone who takes part. Your answers will be completely anonymous. The replies will be analysed by West Berkshire Local Involvement Network (LINK). A report will be published on our web site www.wbna.org.uk and elsewhere. The findings will be used to help inform local NHS and social care managers about how to plan and commission better services in the future.

I would be most grateful if you would complete the form enclosed and return it to WBILN, 4-8, The Broadway, Newbury RG14 1BA in the pre-paid envelope provided, at your earliest convenience. If you have any questions or need help to complete this survey please contact me on johnmholtbsc@aol.com or 01635 33582.

Should you wish to complete the enclosed Healthwatch leaflet with your contact details, that leaflet will be processed entirely separately from this survey.

Thank you for your help and support.

Yours faithfully,

John Holt Liaison Officer

West Berkshire Neurological Alliance

Representing all people in Berkshire West affected by a neurological condition.

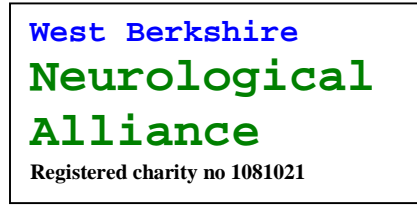
Patrons: Baroness Susan Greenfield, CBE MA DPhil DSc FRCP (Hon). Prof. Christine Collin, MBBS, FRCP. Penny Lilley
MCSP SRP. Prof. Pam Smith Ph D

President: Dr. Steve Allen. **Chairman:** David Roberts. **Vice Chairman:** Irene Waters.

Registered Office: 2, Clayhill Crescent, Newbury, RG14 2NP (Tel: 01635 33582).

Registered

Charity: No. 1081021



Living with incontinence survey 2012

This survey is for people living with incontinence who live in, or use NHS services in the area covered by NHS Berkshire West. The information will be analysed by an independent organisation and recommendations published widely. Please answer the questions by ticking your answers and writing in the comments boxes.

1. From the map above do you live in: West Berkshire Reading Wokingham
2. Are you: Male Female
3. Is your age: Under 18 18-34 35-49 50-65 66-80 Over 80
4. Which of these affects you, and how much?

	Not at all	Sometimes	Quite a lot	Most or all the time
Bladder incontinence				
Bowel incontinence				

5. Do you think your incontinence is linked to a particular condition? Y N

(if yes, please state)

6. Generally, how well are you able to manage your incontinence?

Not at all a little some of the time well almost all the time

7. Do you believe you have all the information, help and advice you need to manage your incontinence as well as you ever could?

Please add here any comments about your answers to questions 4 - 7

8. What impact does your incontinence have on any of the following?

	Very Negative	Negative	Small or no impact	Positive	Very positive
My general physical health					
Condition of my skin					
Bladder infections					
My psychological outlook					
Leading an active life					
My quality of life					
Personal relationships					
My self-esteem.					
Being fulfilled					
Other (please state)					

Please add here any comments about your answers to question 8

9. How easy is it to find the following things that you may need?

	Easy	Fairly easy	Not very easy	Difficult
Timely and suitable information				
Timely and suitable advice				
Effective management options				
Effective products that suit me				
Effective support				
Ways to adapt to change				

Please add here any comments about your answers to question 9

10. How much do you agree or disagree with the following statements?

	Strongly agree	Agree	No view	Disagree	Strongly disagree	Not app
The NHS Continence Service is easy to contact						
The NHS Continence Service is well run						
The NHS Continence Service is well resourced						
I get all my continence care products free from the NHS						
The NHS products I use are the right quality for me						
It is easy to order or reorder continence care products from the NHS						
I have enough space to store my continence care products						
I am given appropriate continence care prevention information from the NHS						

Please add here any comments about your answers to question 10

11. How well do these understand and help you with your incontinence needs?

	Not applicable	Not at all	Small extent	Quite well	Very well
GP					
District / Community nurses					
Continence advisor					
Specialist Continence clinic					
Urology or bladder specialist					
Other hospital staff					
Physiotherapist					
Psychological support worker					
Occupational Therapist					
Social Services Care Manager					
Voluntary sector					
Other (<i>please specify</i>)					

Please add here any comments about your answers to question 11

12. What else would you like to say about 'Living with incontinence? What changes would you suggest, if any, to the way services are provided to people affected by incontinence?

My suggestions ...

13. Which statements best describe your mobility situation? *(please tick up to two)*

- I am able-bodied, without any mobility impairment
- I use a walking aid
- I am a wheelchair user
- I am confined to bed

14. Which of these applies *(please tick one box only)*

I filled in this form myself Someone helped me to complete this form

Thank you for completing this survey. Please return it in the envelope provided to:
West Berkshire LINK, 4-8 The Broadway, Northbrook Street, Newbury RG14 1BA

For further information please contact:

John Holt,
West Berkshire Neurological Alliance,
2, Clayhill Crescent,
Newbury
RG14 2NP
johnmholtbsc@aol.com Tel: 01635 33582 www.wbna.org.uk

West Berkshire Neurological Alliance

Representing all people in Berkshire West affected by a neurological condition
Registered Charity No: 1081021

Appendix 3

Conditions that people felt were linked to their incontinence problems

- 1 Parkinson, too much botox to bladder
- 2 MS
- 4 Astrocytoma T4 Complete
- 5 Ulcerative Colitis
- 6 Stroke
- 7 Alzheimer's disease
- 8 Dementia (Corticobasal Degeneration)
- 9 Spinal Cord Injury
- 10 The bladder is very small and cannot be enlarged any more
- 11 Dementia
- 12 Probably Parkinson Disease
- 13 Parkinson Disease
- 14 Cancer of Colon Operation
- 15 Motor Neurone Disease
- 17 Fracture of CS/6 + Head Injury in RTA
- 18 Alzheimer's and Slow Mobility
- 21 Child Birth
- 23 Depression and alcoholism
- 24 Alzheimers
- 25 CVA
- 26 CVA

Trust helping victims of the 'silent epidemic'

The Trust was among the first in the country to pioneer a new method of treating the "silent epidemic" of Stress Urinary Incontinence which commonly affects new mothers.

The traditional treatment for bladder weakness involves a stay in hospital for surgery followed by up to a month recuperation. However, our Urology Department now offers an alternative and highly effective treatment. Patients undergo a minor procedure to have a special gel injected to help the bladder muscles – normally they will be in hospital no more than a few hours and should be able to return to normal life in a couple of days. Already around 500 women have benefitted from the new treatment. Consultant Urologist Steve Foley said: "SUI is a silent epidemic that women are really scared to come forward and talk about. Injection therapy is a quick and simple procedure to rectify the problem."

Royal Berkshire Hospital - Pulse Winter 2012/13

Appendix 5

Mon 04/02/2013 07:43

Tony

I don't think I have anything to add to this report, though I do believe that those with bladder and/or bowel dysfunction are grateful for a comprehensive assessment from a continence specialist nurse precisely because they do explore a range of conservative treatment options and strategies before suggesting containment as a last resort.

You may or may not know, too, that every six months we organise a flyer distribution to all GPs in Berkshire, the last was at the beginning of January, please see attached, which very briefly describes our service and identifies how they might refer to us. We also organise an extensive training programme throughout the year of full day courses and half day updates on subjects such as continence promotion, continence assessment, catheterisation and bowel dysfunction which is open to all community and practice nurses and GPs, too, of course if they can spare the time.

Furthermore, we have formed close links with the specialist nurses and consultants in MS, Parkinson's Disease and other neurological conditions in Berkshire so that if and when they reach the limit of their expertise in bladder and/or bowel dysfunction they may refer directly to our service.

I'm sure the exchange of information and ideas will inform our service in the future.

Kind Regards,

Terri

Terri Dunbar
Continence Services Manager
Berkshire Healthcare NHS
Foundation Trust

0118 949 5232

Continence Advisory Service
Wokingham Community Hospital
41, Barkham Road
Wokingham
Berkshire
RG41 2RE

teresa.dunbar@berkshire.nhs.uk

Continence Advisory Service

Did you know?

We have a Berkshire-wide Continence Service for patients with bladder and bowel dysfunction

All we ask is that they are motivated to follow a treatment programme to regain their bladder or bowel function

Treatments offered after a specialist assessment include:

- Pelvic floor re-education
- Neurostimulation
- Biofeedback
- Bladder & bowel re-training programmes

Clinics are held in the following venues:

- Upton Hospital
- St Marks Hospital
- Skimped Hill Health Centre, Bracknell
- Wokingham Community Hospital
- Royal Berkshire Hospital
- West Berkshire Community Hospital

Referrals can be sent on the attached referral form to:

**The Continence Advisory Service
Wokingham Community Hospital
Barkham Road, Wokingham, RG41 2RE
Tel: 01189495146
Email: continence@berkshire.nhs.uk**