

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

Appendix 1

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.

Appendix 2

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.

ENDS