



**A Report on the Views
of Service Users and Carers
on the
Provision of Incontinence Pads
July 2009**

**Cumbria
Local Involvement Network
(LINK)**

"Incontinence is soul shattering. It can completely ruin the lives of those of us who are affected by it. Humiliation, degradation and shame are familiar feelings that we experience when facing incontinence"

Person with incontinence, writing to *Incontact*: White (1997)

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Cumbria Local Involvement Network

Local Involvement Networks (LINKs) were established in April 2008 to give people the opportunity to influence local health and care services by representing their views to those responsible for the planning, commissioning and delivery of services.

Local Concerns

Cumbria LINK was contacted by a number of third sector organisations and individuals who raised concerns about the effects of changes to the Policy for Assessment of Adults and Children with Incontinence and Provision of Pads and Garments on service users and carers.

Concerns raised with the Cumbria LINK included:

- A reduction in the number of pads supplied from 6 to 3
- A reduction in the quality of pad provided
- A lack of flexibility in policy - one rule for all no matter what the circumstances
- A lack of consultation with carers or users around policy change
- A Lack of involvement of front line staff had about changes
- People reported that they had not had assessments,
- Increased demands on GP's and prescribing to treat skin infections and rashes

Methodology

A short questionnaire was designed to capture the wider views of service users and carers on their experiences. The questionnaire [annex 1] was made available on line at www.cumbrialink.org.uk and publicised in the local Carers Association Newsletter and Cumbria LINK Newsletter. The Carers Association provided further help in distributing the questionnaire to carers known to them who used this service. Where possible free post envelopes were provided for responses.

Carers were also invited to meet with researchers to give a more in depth account of their experiences.

Incontinence Background

'Urinary incontinence is the unintentional passing of urine. It is a very common problem that is thought to affect about three million people in the UK.

Anyone can experience urinary incontinence, although it is more common in older people. The condition affects far more women than men, and it is thought to occur in one in five women who are over 40 years of age.'
www.nhs.uk

The minority of patients who fail to respond to treatment need appliances and techniques that will enable them to live with their incontinence while maintaining an acceptable quality of life.

In addition to arranging a supply of products and giving guidance in their use, healthcare professionals responsible for managing such patients need to consider the standard of the individual's personal hygiene and skin care and the availability of the necessary laundry and disposal facilities.

Most important also is continued support for the patient and the family aimed at maintaining psychosocial functioning in the face of a long-term continence problem.

Government Targets and Priorities

The National Health Service is under pressure to meet various Government targets and priorities. It can be argued that tackling incontinence effectively can contribute to this public health agenda:

The National Service Framework for Older People 2007 NSF

Sets out eight standards to ensure fair, high quality, integrated health and social care services for older people. Good management of continence services can contribute to these standards as described above. In addition the NFS standard for person centered care outlines the need for managers and professionals to:

- listen to older people
- respect their dignity and privacy
- recognise individual differences and specific needs including cultural and religious differences
- enable older people to make informed choices, involving them in all decisions about their needs and care
- provide co-ordinated and integrated service responses
- involve and support carers whenever necessary

The Government have named "**promoting independence**" as a "national priority", on which Health and Social Services should have a shared lead role (Department of Health, 1998 b). They should seek "to ensure the provision of services which help adults achieve and sustain the maximum independence in their lives", since "availability of timely health and social services in the community can make a crucial difference to the ability of older people to maintain or achieve independence and maintain a healthy active life". The Government has set as an objective to "prevent or delay loss of independence by developing and targeting a range of preventive services for adults" and support for carers. One of the two aims of the White Paper (Department of Health, 1999 a) is "to improve the health of the population as a whole by increasing the length of people's lives and the number of years people spend free from illness".

Good continence services are directly relevant to this objective since incontinence is a precursor to institutionalisation:

Local Considerations

It is well documented that in Cumbria the population has a higher than national average number of older people and it is projected that this number will increase in the future. This together with a decline in the number of working age people in the county presents a real challenge to our health and care services.

Cumbria is a large rural area, making travelling difficult which impacts on the services that can be provided. Local consultations in Health and care are looking for solutions to deliver services closer to home

Cumbria also has a large number of informal carers and it is important to provide adequate support for them. If the carer is unable to cope more people will have to be admitted to long term residential or nursing care (Thorn et al, 1997). at substantially increased cost to public funds

The Department of Health has set it as an objective for health and social services in England to "provide carers with the support and services to maintain their health and with the information they need" in their work of caring:

Inevitably incontinence provides a major source of both physical and emotional strain for carers (coping with the feelings of the person cared for, help with toileting day and night, lifting people unable to move by themselves, constant laundry, lack of personal time, gross intrusion into any social life, etc.) The strain will be demonstrably increased if incontinence is inaccurately assessed and/or inadequately treated, and if inappropriate or insufficient products are supplied and expert support is not available.

The general direction for the future delivery of services in Cumbria is to provide services closer to home so that people can get the treatment and care they need in their own homes or close to where they live.

NHS Cumbria Policy for the assessment of adults and children with incontinence and provision of pads and garments. (November 2007)[annex 2]

The policy states that the 'PCT does not have any statutory duty to provide continence products, however appropriate products can be supplied by the current tender provider to named individuals for whom management of incontinence is a priority of care.'

Adults are assessed to 'determine the type and/or cause of the incontinence and to plan treatment and management programme with patients and/or carers.'

'Where the provision of products is indicated, it must be stressed that the service provided is intended to be supplementary and, therefore, may not cover the full needs of the patient.'

'Any request by the patient for an increase of products must be investigated and re-assessed.'

'Up to a maximum of 3 products in 24 hours should be sufficient for most needs, providing that the correct product is used appropriately.'

Findings

In total 25 people completed the questionnaire and one face to face interview took place. The full survey results and interview notes can be seen at annex 3

We do appreciate that the PCT has no legal obligation to provide free pads to people who live with incontinence, however, given current NHS Strategy it would make sense that people are supported to stay at home wherever possible.

Our findings demonstrate the very individual needs of service users. Some reported that their needs were fully met by the current provision however others struggled with the current level of supplies. Most reported that they tried to make do with the free supplies.

Assessment

From our findings there seems to be inconsistencies in the assessment process. The majority of respondents 72% reported that they had had discussion with health professionals about their needs but 20% said this had not taken place. 40% also reported that no discussion about needs had taken place in the last 12 months.

PCT Policy states that review should take place at intervals no longer than 12 months although it is unclear from the policy whether this refers to the provision of pads.

Supplementary Provision

Policy states that: 'Where the provision of products is indicated, it must be stressed that the service provided is intended to be **supplementary**'. We are unclear how the supplementary figure is arrived at for each individual.

Meeting Needs

52% said that their needs were fully met in terms of supplies of pads, 36% said their needs were not met with current supplies.

48% said that they did not buy extra pads with 16% who said they did buy extra pads. The majority try to make do with the free supplies provided. Those who did make do with free supplies reported that they suffered from sores, rashes, infections, falls and feeling less sociable.

40% of respondents had requested more supplies to meet their needs and 16% were given additional supplies

The Pads

We have had a number of comments about the pads themselves. A disabled lady found them unusable as she could not dress herself again after visiting the toilet. Others reported sores and rashes and that the pads leaked.

Disposing and storage of pads also caused problems and concerns. With a move to 2 weekly refuse collection disposal issues are of increasing concern.

Patient and Public Involvement

Many people we not informed or involved in the changes to policy until it had been implemented although we are informed that testing of the new pads had taken place with some services users.

General

People are without a doubt grateful for the service provided and there were several comments that described satisfaction. Sadly people have expressed a reluctance to talk to us for fear of losing the free pads.

Recommendations

The Cumbria LINK are pleased that Cumbria PCT have a continuing commitment to provide people living with incontinence with free supplies of pads. We would hope that this will continue as it clearly supports the closer to home agenda and provides valuable support to unpaid carers.

We note that the Policy is overdue for review (Nov 2008) we would recommend that a more comprehensive survey of service user needs be undertaken to inform the policy review. The Carers Associations, Age Concern and other appropriate Third Sector organisations are very aware of the issues and concerns and would help inform policy makers.

The quality of the pads themselves has been raised as an issue and whilst value for money is important, quality is equally important and recommend that this be a key element in contract review.

We would like to see a more flexible policy that allows higher levels of supplies to support people to continue to stay at home, support carers and reduce incidences of sores and rashes. Many of our unpaid carers struggle to make ends meet and with the increased pressure caused by the current financial situation poverty is a real concern.

Disposal of used pads is a growing concern; we believe that service users would appreciate advice on safe disposal procedures.

Information Sources

Department of Health
Bladder and Bowel Foundation
NHS Cumbria

Contact Details

Cumbria LINK can be contacted via the Host Organisation, Cumbria CVS

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Survey of User and Carer Views on the Provision of Disposable Incontinence Pads

The Cumbria Local Involvement Network has been set up to represent the views of service users and carers on issues that matter to them. We would appreciate a little of your time to complete this short questionnaire about the continence service.

Please return your forms to us by Monday 30th March 2009. Our address and contact details are at the bottom of this form

1. Has your health/social care professional talked to you about your particular needs?

Yes No

2. Has your health/social care professional spoken to you about your needs in the last 12 months?

Yes No

3. How many free disposable pads do you receive per day?

1 2 3 4 5 6

4. Is this number enough to meet your needs?

Yes No

5. If not, do you buy extra pads?

Yes No

6. How many extra pads do you buy each day?

7. How many pads would fully meet your needs each

8. Do you try to make do with the free supply you are given?

Yes No

9. If you make do with the supply you are given have you experienced any problems? Please look at the list below and tick all that apply to you:

- Rashes
- Sores
- Infections
- Falls when trying to get to the toilet
- Feel less confident to go out
- Feel less sociable

Please tell us about any other problems you have experienced:

10. Have you asked your health/social care professional for more pads?

Yes No

11. If yes were you given more?

Yes No

12. Could you let us know if you have any problems with:

- Storing your supply of disposable pads
 - Disposing of your pads
 - Opening the boxes/bags of pads
- (Please tick all that apply to you)

13. Please use the space below to leave any comment about the continence service.

Thank you for taking the time to complete this questionnaire. The results will be given to the people who commission and provide this service to help them to understand your needs better.



Incontinence Pads Survey March/April 2009-04-03

25 Questionnaires were returned completed

1. Has your health/social care professional spoken to you about your particular needs?

Yes	18
No	5
No comment	2

2. Has your health/social care professional spoken to you about your needs in the last 12 months?

Yes	13
No	10
No Comment	2

3. How many free disposable pads do you receive per day?

0	6
1	0
2	6
3	9
4	4

4. Is the number enough to meet your needs?

Yes	13
No	9
No Comment	6

5. If not do you buy extra pads?

Yes	12
-----	----

No	4
No Comment	9

6. How many extra pads do you buy each day?

0	15
1	5
2	2
3	2
4	0
5	0
6	1

7. How many pads would fully meet your needs each day?

0	14
1	1
2	5
3	0
4	1
5	2
6	0
7	1
8	0
9	1

8. Do you try to make do with the free supply you are given?

Yes	15
No	4
No Comment	6

9. If you make do with the supply you are given have you experienced any problems? Please look at the list below and tick all that apply to you.

Rashes	6	
Sores		4
Infections	3	
Falls when trying to get to the toilet		2
Feel less confident to go out	3	
Feel less sociable		3

Comments on other problems

Pads supplied were square sheets and mesh panties to keep in place. I'm unable to use these. No alternative available.

My husband needs someone with him all the time as he keeps falling when trying to do things himself.

I buy the Boots padded pants for appearance they look like normal underwear.

Wet clothing and bedding.

Mum has only just received the supply so too early to say.

Sore's on patients legs where nets rub.

Didn't know this service existed before now.

School and Huntley Ave respite change pads more often and hence I run out of supply.

10. Have you asked your health/social care professional for more pads?

Yes	10
No	11
No Comment	4

11. If yes were you given more?

Yes	4
No	7
No Comment	14

12. Could you let us know if you have any problems with:-

Storing your supply of disposable pads	7
Disposing of your pads	5
Opening the boxes/bags of pads	2

13. Please use the space below to leave any comment about the continence service.

Number allowed not sufficient. Local Health Centre will not provide extra. Purchase of extra pads proves expensive - try to manage with given amount - therefore health problems i.e. soreness

Very good service

No one come to see us to discuss the service, although there are no problems with the helpline or delivery.

In between delivery of pads every 12 weeks I run out 3 weeks before next delivery and have to buy extra to next delivery date

No regular check up in place for patients. Regular purchase of baby nappy bags required to dispose of soiled pads. Nappy bags tend to be too small.

The health visitor came to see me asking questions about incontinence. I asked 'what is this in aid of?' she said 'I need to know if your incontinence is sufficient to qualify you for free pads and it is' I said 'suppose it wasn't' 'well you could have the operation.' This means that people who do not qualify have no choice about the operation unless they can afford to pay for pads.

The only pads which I am able to be supplied with are utterly unsuitable. I only have the use of my left hand, so am unable to dress myself again after a visit to the toilet. The only pads that I can manage myself are those shaped like panties, and these are not available. I have to rely on my carer buying pads from Boots for me to use.

We have a coal fire and burn the pads. We are very pleased with continence service

The soiled pads go with normal refuse and I wonder about the environment. Ref to Q6, It varies, day pads are no problem and most nights he needs two. I usually buy 1 pack.

I am still adjusting to Marjorie's needs at present we are coping, I will contact if needs be

On leaving the Cumberland Infirmary last July/August I was given a few pads by the sister on the ward (Beech) since then I have bought my own as the free issue service wasn't mentioned to me. and I hadn't thought that such a service existed.

No one allows for the wearer to be ill when double the number of pads can be used. Type of night pants supplied not easy to use - pad with net pants. Mum would have difficulty doing this herself

I am very grateful for the free pads

Overall very good and satisfactory

Pads are described by manufacturer as maximum capacity, but it's not much good if they leak before the pad can retain the fluid!!

Annex 3

Incontinence Pads Survey

Interviewed carer of disabled doubly incontinent individual
Interview took place Thursday 4th June 2009

There was a letter sent out 2yrs ago telling clients that they would be getting their pads through a new supplier (Abri). Previously they had all received different types of pads through different suppliers. There was no mention of reduction of supply and no consultation.

When the pads arrived they used them and then phoned for more as they had done previously but were told they had had their full allocation for three months and gave them the date for the next delivery. The carer phoned the incontinence service at the hospital and was told they now only had 3 a day instead of the usual 5.

If they require more they have to buy them at a cost of £45 per pack. Can't compare to the previous supply as they don't know how much the previous ones cost.

Originally they had a choice as the nurses used to visit and bring pads to try so they could find one that suited them

There are huge problems with sores and boils for which he has to have antibiotics from the Dr. There was problems with the old pads but not as sever as with the new ones. They have been changed to the Air Plus ones which are slightly better but they have to be careful and keep on top of things, but he still breaks out every 2-3 months and has to be treated by the Dr. Even the Dr has commented on the effect of the new pads and said he would look into it but hasn't got back so far.

Storage of the boxes is in the garage but feel lucky that there is a garage because those that don't have a huge problem with storage. The carer just hopes the mice don't get in!

It has been two years now so they have got used to it and just get on with it. They did initially complain but were told that they were lucky as people in other areas of the country didn't get any at all. They were made to feel that if they carried on complaining then the allowance would be stopped and they wouldn't get any at all