

## Wiltshire & Swindon Users' Network – Contenance Redesign

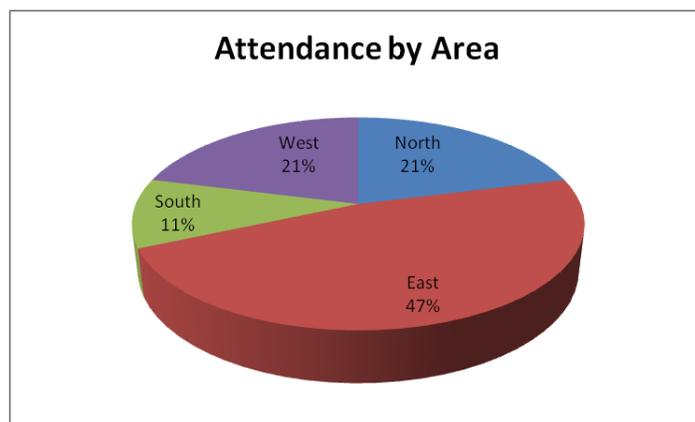
**Date:** Monday 9<sup>th</sup> December 2013

**Venue:** Sun Room, Independent Living Centre, Semington

**Time:** 10:30 – 12:30

### Transport for WSUN members

Number of people requesting transport:	9
Number of people who actually came by taxi/arranged transport:	8



### Speakers

- Angela Billington - Wiltshire CCG

### Support for Members

We booked one enabler to support guests on the day.

Including staff members the total number of people who attended was 12

Three other service users fed in their answers to questions over the telephone

Other experiences were recorded from anecdotal evidence during Mediquip and Help to Live at Home Monitoring.

### Questions

A set of questions was given for members to respond to and to act as the basis for further discussion.

### Louise Rendle, Head of Network Services

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## **1. If you have used the continence service, which part have you used – clinical nursing or pads?**

- What were your first impressions?
- What would you like changed if anything?

A few people present have used the service. One reported that they had been provided with the wrong sized pads and ended up paying for their own for many years despite the fact they had reported that the ones provided were not suitable. Other service users reported it was common for friends to buy their own pads as they were not happy with the ones provided especially after a change in the provision of pads. One person reported they were not happy that the new pads did not seem to offer the same level of odour control as other makes eg. Tena and so they were conscious of this and did not like going out of the house.

## **2. Delivery of pads through Medequip**

Experiences of delivery of pads by Medequip were mixed with some reporting that deliveries were generally ok but improvements could be made. For example, one person reported that their delivery had been left on the doorstep against their request and they were not able to move the boxes themselves.

It was felt that the Medequip service and products needs more promotion as it is not widely known about. These should be advertised in all GP surgeries, chemists etc.

Although many could not comment on the service overall it was felt that such a service should be prompt, with deliveries being made on at the time and day stated by Medequip. The service should also be caring, understanding and polite. Delivery drivers should have training and awareness of customers' situation and that the customer might feel awkward or embarrassed.

## **3. Experience of using pads, catheters or sheath appliances**

Charter Care were reported to provide a very good service but now have to give 2 weeks notice and get prescription from GP. This means having to plan well ahead for holidays which some people might struggle with. The CCG now have to authorise all expenditure, one person reported that whereas Charter used to be able to turn orders around in 2-3 days it was now a 2-3 week wait.

Problems were reported with catheter connections not always being very good. It was felt that more support should be given when catheter first fitted. Problems were encountered when leaving hospital after a catheter was fitted. No information

was given about reordering the equipment (catheter bags etc.), No information about how to look after your catheter. A night bag stand was not provided. It was not always made clear who would change a catheter or who to contact if any concerns. It was queried why a catheter is left in for up to 12 weeks. Angela Billington was able to answer this question explaining that changing it less frequently reduces the risk of infection. However, this query highlighted that perhaps this is not always explained sufficiently when catheter is first fitted.

Another person reported that care after a suprapubic catheter was fitted was abysmal. On discharge they were given one very basic leaflet and no advice how to look after themselves or what to look out for. It was only when the district nurse came over 6 weeks later that they were given aftercare advice.

District nurses were not always aware when a patient had come home from hospital with a catheter or when the catheter next needed changing.

Storage of pads was a significant issue as many people live in small one bed flats and simply do not have space for storing six weeks supply of pads. They end up being kept all over the home and it is embarrassing when visitors come and there are boxes of pads in the lounge. One person suggested boxes could be vacuum packed to take less room, also that smaller but more frequent deliveries could be provided.

Collection of pads was also reported to be an issue as not frequent enough resulting in bags of used pads being piled up outside house.

Some people felt that there was not enough choice of pads and suitable pads are not available.

No allowance made for variation of use, people may have good or bad days, where more pads are needed.

#### **4. Areas of general discussion**

##### **Awareness**

Awareness issues tended to fall into two main areas; awareness of services and awareness of continence issues.

Not everyone is aware of the services which are available. After sending information about the consultation WSUN received a call from a lady who had been buying pads for some time and was totally unaware that there was a service which

could help her. She said that she would call her GP straight away to see what support she can get.

There needs to be information about the continence services in GP surgeries, libraries, on internet etc. There was some knowledge of the availability of a free phone telephone number but this should be on every public toilet door.

Continence is an issue which is rarely talked about. It is difficult to find help due to embarrassment. There is felt to be differing advice given to people with older people getting three different responses from GP, District Nurse, and Incontinence Service. There is stigma relating to personal care needs and issues around finding the right support.

Some people do not know that you can be assessed or that pads can be provided free from the start.

### **Professionals Approach**

People expressed a concern about issues not being investigated by specialists when needed. For example, someone with Multiple Sclerosis reported that their continence issue was not treated as such but put down to her MS. All present agreed that the 'patient' must be seen to be the expert of their situation. Services need to take a holistic approach (co-ordinated by GP) in their assessment and care of patients.

### **Waiting for services**

Others expressed that the wait for services is too long – up to 8 weeks was reported and that people have to chase up services. It was reported that the Assessment Service need regular chasing. It was also noted that the assessment process needs to be a 'can do' service. There was a perception that the need for a GP signature could sometimes delay delivery of pads.

### **Care Homes**

Care homes were noted as facing particular challenges in managing continence. Staff do not have enough training and experience in looking after people with catheters. Homes use pads inappropriately in some circumstances when they should be giving more care and increasing people's dignity.

### **Care Agencies**

Care Agency staff were not always aware of how to look after people with continence issues, particularly the importance of catheter care. People reported that they were required to empty catheters into a bucket (high risk of infection especially if the buckets were not washed out). Carers were not always attaching night bags resulting in safeguarding issues. Some carers were attaching leg straps to catheters incorrectly (over the top of the bag and blocking tubes). Several instances were reported of leaving the tap in the empty position, causing the person to be drenched during the day.

### **Diet, hydration and exercise**

It was widely agreed that lots of people do not drink enough because of worries about needing to go to the toilet more. Diet and hydration are so important and need sharing more across all ages. Exercise is vital and could be taught at an early age, pilates etc is very beneficial.

### **Other issues**

Other issues raised included the gap in the market for 'trendy' pants and pads and more options for underwear and incontinence management supports. It was questioned whether washable products could be viable.

The CCG should have an overall view of all services and support and ensure that the whole of Wiltshire is offered the same – not a postcode lottery.

If someone has a fall then GP /A&E should investigate if this relates to their trying to get to toilet and ask questions about their continence. If conducting a routine health check as now offered to all over 40 years of age, GP should discuss night toileting (especially with men) as part of the health check.

Education of general public is essential especially for new mums and men over 50 years. More advertising of the continence service and information available showing that there are things that can be done to help with some continence issues like stress incontinence.