



Working with community groups and clubs, so we can understand local peoples' views; concerns and experiences



Urinary incontinence is the unintentional passing of urine. It's a common problem thought to affect millions of people

October 2018

What we understood so far

Through our recent engagement we are hearing peoples' struggles to get information, advice and support, to help them with their incontinence.

This led us to look at this issue more closely and to report our findings:

- **A lack of signposting on where to buy continence products**, for people waiting to get seen by the incontinence service, which could be months of waiting
- **No easy process for arranging for the disposal of used products**
- **Confusion arising from differing information** from NHS, District and Borough and County disposal
- National information is not easy to find or follow
- The NHS and local authorities may be paying for the same service and therefore duplicating public spending
- People want to do the right thing and dispose of the products correctly, but obstacles are placed in their way*

*Healthcare professionals (usually primary care) are required to sign local authority forms so residents can get soiled items collected appropriately. We heard multiple reports of completed forms then not being received by local authority, which leads to long delays.

Why this should be of concern to us all?

Incontinence affects people indiscriminately. Brian and Joyce were amongst a local group sharing their concerns around support and information for continence problems

Brian caring for his wife told us, 'I have been married for over 50 years and never thought I would have to do things like this'.

Joyce told us 'I have been trying to obtain the 'yellow bags' from West Sussex County Council for incontinence items. I have filled in the forms and been told they have not been received or been lost. It is so frustrating'.



- People living with long term conditions, and their family and friend carers, have much to contend with. The current processes and systems for supporting people who live with incontinence, make their lives more difficult and add unnecessary complications
- The health of the public should be kept in mind when looking at processes and systems, and delays caused by these
- A lack of joined up thinking could lead the NHS and local authority spending more public money than they need to.

What needs to change?

There needs to be:

- a consistent approach to communication around the purchasing and disposal of incontinence products
- An easy system for getting waste collected in a safe and dignified way
- A timely way of getting support and information.

Fortunately, the time is right. We understand the existing waste contract is due to be reviewed for recommissioning soon, so now is the perfect time to resolve these issues.

We therefore make the following recommendations to West Sussex County Council and local Clinical Commissioning Groups:

- County Council contract team meet with the appropriate commissioners within the local Clinical Commissioning Group to:
 - maximise their buying potential and avoid potential double-payment for incontinence waste collection
 - together challenge the need for primary/community clinicians to sign the application forms for soiled waste collection
 - agree the wording for all public information on disposal of incontinence products and make this information and advice available to all district and borough organisations, the NHS and voluntary sector organisations.
- Access to appropriate soiled waste collection for people living in their own homes is made simple and delivered properly, to reduce the burden on residents and to reduce the risk of this type of waste not being processed appropriately
- West Sussex County Council looks at the Adult Social Care Financial Assessment process to satisfy itself that the cost of purchasing incontinence products is deducted from individuals' available income (as a disability related expense) when they are examining what a person can pay towards their social care.
- West Sussex County Council works with all locally commissioned information and advice services, to support them to have the correct information on the disposal of incontinence products, and details of where people can purchase incontinence products and what would be a reasonable cost for such items.

