

## Feedback to CDHB regarding people's experiences of continence care following stroke

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This feedback is collated from research interviews conducted with 7 people following stroke (PFS), who were living in their own home, and managing post-stroke bladder and/or bowel incontinence. There were more men than women, age ranged from mid-50's to mid-80's, and time since stroke ranged from 2 and 14 months.

The aim of the research was to explore how PFS managed incontinence in order to participate in activities and life roles that are important to them. This work is the first part of a research programme that will work with PFS to develop an intervention supporting people's participation in the context of an ongoing need to manage incontinence.

In the interviews participants talked about experiences of continence-related care in the inpatient rehabilitation setting; these reflections were shaped by what they now knew about managing continence issues at home. Inpatient rehabilitation staff may not often get the opportunity to hear of their patient's experiences once discharged. We thought staff might therefore find it interesting and useful to hear a summary of key findings from the interviews to support discussion about the nature and provision of services, and how well people's needs were met.

Three particular issues emerged: 1) coping at night; 2) who will talk to me (us) about it and where can I (we) get help that helps?; and 3) one size (solution) does not fit all, all of the time.

We don't wish to make judgements about people (patients or staff) and what happened or did not. We do want to facilitate discussion about ongoing service improvements in this area, and how this can be part of the continuous quality improvement cycle of the interdisciplinary inpatient team. Rachelle and Jean are very happy to participate in any discussions you may have if this is appropriate and/or helpful.

### Coping at night

Imagine you're the PFS – your affected side is stiff and sore from spasticity and your leg jumps in the bed at night; you wake quite often and when you do you experience bladder urgency and feel you have to get up right now to get to the toilet; it's hard to roll over in bed and you get tangled in the sheets; by the time you get up the flow has already started and the bed is a bit wet; you get to the toilet but it's hard to get your pyjama trousers down with just one hand and balance at the same time; the floor gets wet and slippery; you've tried a urodome but it falls off about two-thirds of the time and the pull-ups are difficult to get up and down on your own; you're up to the toilet 3 or 4 times a night.

What about the spouse of the PFS? – you sleep in the same bed and know he’s restless and sometimes he kicks you without meaning to; when he’s struggling to get out of bed you feel him thrashing around and get up to help; you walk with him to the bathroom to make sure he doesn’t fall and help to try and get his pyjama bottoms down; while he’s on the toilet you change the kylie, and then when he gets back to bed you wipe up the bathroom floor; you try your best with the urodome but “it just disappears when it sees you coming” and getting the urodome on properly is difficult; pull ups are better but you still need to get up to help with them or he gets stuck; even if you leave him to it, you’re awake every time he has to get up; there is extra laundry every day (PJs or sheets or towels from mopping the floor).

What we heard was that lack of sleep at night, much of it as a result of managing bladder urgency and frequency, had a much bigger impact on the wellbeing of PFS and their partners (who are providing care) than anything that was happening during the day. Frequency of toileting at night contributes to very high levels of fatigue for both PFS and their partner. This results in significant stress and distress. Partners were not aware of the extent of care that required once the PFS was discharged (and the implications that has for them as carers) and some reported that they would not have taken the care role on if they had known. The hospital environment (e.g. bed with grab rail, smooth flooring, floor lighting on all night, urodome applied by an experienced nurse) and home are quite different and neither the PFS nor carer were prepared from the implications for night-time toileting.

#### Who will talk to me (us) about it and where can I (we) get help that helps?

The common experience for the PFS and partner was that no one during inpatient rehabilitation initiated a conversation about bladder and bowel issues, even if these were obvious, i.e. the PFS was being asked “do you need more pads?” There were some instances where a person had felt ‘told off’ when staff needed to ‘clean up’ after an accident, or reprimanded for walking unaccompanied to the toilet because the experience of urgency meant they couldn’t wait for their call bell to be answered. What was wanted was genuine conversation about the issues and their impact, and it seemed this wasn’t offered even if the PFS felt they gave clear signals such a conversation was sought.

Inpatient continence support was delivered as ‘fait accompli’ and the PFS and/or partners did not feel part of the process or included in decision making around what might work best. All the continence management was left to nurses to do, even if other health professionals knew there were bladder or bowel problems. Partners particularly felt they knew little or nothing about managing continence. This was a problem because once the PFS went home it was totally up to them (and their partner) and often what they had observed (or used) in hospital was not the same at home. For some, while in hospital, there was little sense of bladder filling but once home they experienced the most profound and overwhelming sensation of urinary urgency that could not be controlled. This was a big shock.

At home, continence management was shared in the PFS/partner dyad. Partner stress and distress was a real concern for many PFS, impacting on their decisions as to what products to use (e.g., they may choose a more absorbent product to reduce the work of incontinence for their partner) and what the level of 'independence' they may aspire to.

PFS and their partners were very confused about who (and where) to access ongoing support from. If they do know who to contact, they are not sure when they should be in contact, or are often too overwhelmed with the daily work of care to ask for help. Leaflets/written information were of limited use because the advice wasn't personalised.

### One size (solution) does not fit all, all of the time

While all the participants had a bladder and bowel 100% of the time, it didn't feel they had the same one 100% of the time – certainly they could not rely on how the bladder and bowel would be day to day or week to week. This made it very difficult to have only one 'solution' because the PFS and partner needed – but didn't have – the skills/knowledge/experience to respond flexibly. Commonly they had not experienced any variability in how bladder and bowel were managed in hospital – one size fits all – and this meant they had little resource to experiment with once they were home. Also, in hospital management was not always effective (e.g. regular urodome failure) and this was, nevertheless, the unquestioned plan for managing post-discharge.

Further, bladder/bowel function and management could not be separated from the other effects of the stroke. For instance, how much and what people ate and drank changed post-stroke and this changed bladder/bowel function and in turn what the PFS ate and drank was changed again to try and manage problems such as leakage or constipation. If the body was stiff and sore, or numb and unresponsive, this made mobility more difficult and toileting more difficult in turn. If fatigued, it was harder to manage everything or find energy to try different things.

### Reflection questions.....

- What words could we use to start a conversation?
- What are good times and places to initiate a conversation?
- What opportunities are there for partners/unpaid carers to be included in conversations?
- What are the opportunities for practice in hospital?
- What could be done to start building a 'bridge' from hospital to home until the PFS and partner find out what it really is like at home?

- What are some ways of coping at night that we and the PFS stroke could experiment with in hospital, or what problem solving could we do using resources in hospital to help them think ahead to coping at night at home (e.g. use a night shirt in hospital? Which side of bed to get out of versus side of the bed they sleep on at home?)
- What team processes could be used to ensure that continence self-management remains prioritised within the constellation of post-stroke concerns and issues?