

# The **Thalidomide** Trust

## Bladder and Bowel Problems

### Briefing Paper (Final - May 2017)

#### 1. Introduction

One of the striking findings from the 2015 Health and Wellbeing survey was the number of beneficiaries who reported having bladder and/or bowel problems - 72 (20%) had bladder or continence problems and 98 (28%) had bowel or digestive problems. Moreover, people were often coping with these difficulties alongside their original Thalidomide damage and other health issues, notably secondary musculoskeletal problems. Not only does this create significant practical challenges (e.g. having to undress frequently and/or quickly with upper limb damage), it can be physically and emotionally draining. The work of the Health & Wellbeing Team, and qualitative research carried out as part of monitoring the Health Grant, showed that bladder and bowel problems can be very distressing and they often affect peoples' quality of life and mental wellbeing. It also suggested that some beneficiaries do not seek medical help with these problems. However, many have sought help and had treatment, and there may be lessons to learn from their experiences which could benefit other beneficiaries.

The Trust was keen to get a better understanding of the bladder and bowel problems beneficiaries are experiencing, so that they could look at ways to improve the support and advice offered to beneficiaries. In particular they wanted to explore whether these problems were recent or longstanding, the impact they were having on peoples' lives and the treatment or self-management approaches that had made a difference. This paper presents the findings from a small piece of research commissioned to examine these issues.

#### 2. Approach

There were two ways in which beneficiaries could contribute to the research – by completing a short survey (on line or by post) or by taking part in a telephone interview. The invitation to take part in the research was sent to 72 beneficiaries who reported in the Health & Wellbeing Survey that they had bladder/continence and/or bowel/digestive problems and said they were happy to be contacted about further research. Eighteen people completed the survey (five men, nine women and four not stated) – a response rate of 25%. This response was a little disappointing but those who did reply often provided a great deal of information about their problems and how they were dealing with them. In addition, eight beneficiaries (two women and six men) participated in telephone interviews held in late February and early March. The interviews were recorded and transcribed as detailed notes and quotations. The findings from both sources are brought together in this briefing paper.

#### 3. Bladder Problems

In the survey, a total of 13 respondents (72%) said they had some type of bladder or continence problem. Of these 11 also had bowel or digestive problems. Understandably people described their problems in lay language but broadly speaking, they fell into four common types of urinary incontinence<sup>1</sup>:

- Urge incontinence – or urgency incontinence, when someone feels a sudden and very intense need to pass urine and is unable to delay going to the toilet. The need to pass urine may be triggered by a change of position, or even by the sound of running water.
- Overflow incontinence (chronic urinary retention) - when someone is unable to fully empty their bladder, which causes frequent leaking
- Stress incontinence –when urine leaks out at times when the bladder is under pressure e.g. coughing or laughing
- Mixed incontinence - when someone has symptoms of both stress and urge incontinence.

Seven respondents appeared to have urge incontinence. Some used the terms ‘urge incontinence’ or ‘irritable bladder’, whilst others said things like – *“I have poor bladder control”* and *“weak bladder – can be caught short”*. Four described the symptoms of overflow incontinence, as this beneficiary’s comment illustrates – *“I am always wanting to urinate only to find my bladder isn't very full at all and perhaps pass around a 1/4 of a tea cup”* (Survey Respondent 5). Two had mixed incontinence, with one describing it in the following way – *“Bladder leakage, especially when coughing or sneezing [and] cannot hold for too long before visiting the bathroom”* (Survey Respondent 3).

As Table 1 below shows, half the survey respondents had only developed bladder and continence problems in the last ten years.

**Table 1 Number of years experiencing bladder/continence problems**

How long having problems	Number of Respondents
1-5 years	6
6-10 years	3
More than 10 years	4
Not stated	5
Total	18

Four male beneficiaries (one in the survey and three in the interviews) noted that they had only begun to have problems in recent years and speculated that it may be related to age and changes in their prostate:

<sup>1</sup> Taken from the NHS Choices website. See <http://www.nhs.uk/Conditions/Incontinence-urinary/Pages/Symptoms.aspx>

*“In recent years I have noticed myself needing to pee more frequently. I understand that this is a common issue with men of my age! It seems to bear very little relation to how full my bladder is. If I am filling a kettle, the sound of water makes me want to pee. There may be very little in my bladder but I still feel 'desperate' to go”. (Survey Respondent 9)*

A few beneficiaries explained that they had experienced some bladder problems all their lives but that they had got worse in recent years. One female beneficiary said she had always had to get up once or twice in the night to go to the toilet but now it is not uncommon for her to get up six or seven times, whilst a male beneficiary said that his urge incontinence has got worse as he had got older.

### **3.1 Causes, Diagnoses and Medical Treatment**

The majority of participants had seen their GP about their bladder and continence problems and of those that hadn't, the main reason was that they didn't think anything could be done. Five survey respondents and two interviewees had been given a diagnosis and all of them had been referred on to either a hospital consultant (Urologist or Gynaecologist), a continence nurse or a physiotherapist (one person had paid to see a physiotherapist privately). Some had been given advice about drinking more water to dilute urine and reducing caffeine intake, one had been given advice about how to sit to maximise emptying her bladder. Another had been given detailed advice and bladder retraining exercises by a (private) specialist pelvic physiotherapist and she said this had been one of the most effective things she had done.

Five beneficiaries said that they had gained some benefit from medication, in particular a drug called Vesicare which reduces bladder sensitivity and enables people to go for longer periods without needing to urinate. One beneficiary said that it had made a huge difference to him both socially and practically e.g. he could now sit through a film and drive for longer periods. A few beneficiaries felt that their bladder (and bowel problems) were in part related to anxiety or at least made worse by anxiety, and one noted that counselling for this and other issues had helped. Lastly one beneficiary had been offered surgery to address his bladder problems but as the procedure might have affected his sexual function he had declined it.

## **4. Bowel Problems**

Seventeen survey respondents and all eight interviewees said that they had bowel or digestive problems. Of these 25 beneficiaries, 17 also had bladder or continence problems. Seven participants said they had 'irritable bowel' or Irritable Bowel Syndrome (IBS) and one had diverticulitis<sup>2</sup>.

However, several more described symptoms which are associated with IBS, in particular: stomach pain and cramping; a change in bowel habits – such as diarrhoea, constipation, or sometimes both; bloating and swelling of the stomach; excessive wind (flatulence); and experiencing an urgent need to go to the toilet<sup>3</sup>. Importantly people with IBS may also be more prone to bladder problems, such

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<sup>2</sup> In diverticular disease, small bulges or pockets (diverticula) develop in the lining of the intestine. Diverticulitis is when these pockets become inflamed or infected.

<sup>3</sup> Taken from the NHS Choices website. See <http://www.nhs.uk/Conditions/Irritable-bowel-syndrome/Pages/Symptoms.aspx>

as needing to urinate more often. The quotations below vividly illustrate the symptoms people were experiencing:

*“Always had a sensitive stomach, but has got worse as I've got older, have to visit the loo 3-4 times every morning and again in the evening. Sometimes cannot control bowel movements as they are so violent and there is leakage before I make it to the loo”. (Survey Respondent 3)*

*“Irritable bowel - I can go from constipation to expelling just lumpy 'water' and suffer terrible cramps...Once I start to get the first gripe I need to get to a toilet ASAP. I have been known to get out the car on a country road and use the grass verge and I can soil myself”. (Survey Respondent 5)*

*“Daily digestive discomfort/pain/nausea which can occur at a moment's notice and at any time of the day or night. Depending on the severity this can have a knock on effect to bowel movements”. (Survey Respondent 10)*

A number of participants said that they experienced severe bouts of constipation and/or described their digestive system as “*sluggish*”, and for two this had led to anal fissures. A few beneficiaries felt that their problems with constipation were in part a consequence of their Thalidomide damage in that they had spent much of their lives trying to control their bowel movements so that they didn't have to use toilets away from home and/or to reduce the number of times they had to undress and dress. Many have also restricted their fluid intake (for the same reasons) and this may also have contributed to constipation problems (because of lack of moisture in the bowel). One interview participant explained that he had always gauged his fluid intake so that he didn't need to go to the toilet at work and whilst traveling to or from work but this had begun to cause problems:

*“That has started to have a knock on effect in that over the last couple of years I've noticed pains in my abdomen, and I've had a couple of occasions when I've been incredibly constipated, to the extent that I've cut myself when I have gone to the loo...recently, I had such bad constipation that I ended up going to casualty. I thought I had a real problem. They x-rayed me, did blood tests and all sorts of stuff and it was just massively compacted matter inside me”.*

He then went on to say:

*“When I came across this [bowel problems] in the Firefly Report...firstly I was quite surprised because I hadn't considered that aspect that I was being affected by was in any way related to the disability but then the more I thought about it and the things that I do and the way that I was treating my body in certain respects were actually causing it, and why I was having to treat my body in that way was as a result of the disability. It was actually quite a revelation putting those things together.” (Interviewee 4)*

Lastly, a few beneficiaries were experiencing digestive problems, in particular acid reflux and swallowing difficulties which appeared to be unrelated to bowel problems. One beneficiary had

recently been diagnosed with acid reflux which was now being successfully treated with medication but only after years of stomach pain and damage to her teeth (from the acid):

*“I’ve had these stomach pains on and off for 20 years. I used to put them down to one or both of my ovaries being enlarged before I was due for a period but it’s obviously something that been there for many years because since he’s put me on the medication I think I’ve had one serious stomach pain in the last two years”.* (Interviewee 5)

A few participants said they had had bowel or digestive problems for most of their lives, although often they had got worse as they got older. One interviewee who recalled having stomach pain and constipation since his teens but these problems had gradually got worse and had been exacerbated by working long hours and eating irregularly. He explained:

*“I was in my forties when they told me I’d got irritable bowel syndrome. I’d had it a long time before anybody really realised and then the gall bladder decided it wasn’t going to work anymore, and then once they took the gall bladder out, obviously all hell broke loose because the acid that was in my stomach wasn’t being purified in any way at all”.* (Interviewee 3)

The majority reported that they had only started to experience significant problems in their forties but some also suggested that they may have had low level symptoms for longer. One participant reflected – *“In retrospect I believe I have had this condition as a background problem for many years”*. Table 2 shows this information for the survey respondents.

**Table 2 Number of years experiencing bowel/digestive problems**

How long having problems	Number of Respondents
1-5 years	6
6-10 years	5
More than 10 years	6
Total	17

#### 4.1 Causes, Diagnoses and Medical Treatment

All the interviewees and the majority of survey respondents had consulted their GP about their bowel and digestive problems but several acknowledged that they had delayed doing so for months or even years, until the symptoms became too severe or their partner pushed them to go. One participant explained that it was attending the Fit for the Future weekend that had encouraged him to seek help with his longstanding bowel problems. For some this reluctance was a legacy of their childhood experiences of doctors - *“I had many operations on my hands and arms when I was little. I hated hospital and I hated doctors, and it took me 30 years to become more even minded about it*

*and more prepared to go to a GP” (Interviewee 2). Others feared that they may have a more serious condition such as cancer, whilst a few simply felt it was unlikely that anything could be done.*

As was noted in the previous section, several participants had obtained a diagnosis of their problems, usually after seeing a hospital specialist such as a gastroenterologist. The majority had also received some treatment - eight been prescribed IBS or antacid medication (with mixed effectiveness), four had been given osmotic laxatives and three had had surgery. Only one person had been referred to a dietician but another had sought help from a dietician privately and some had been given dietary advice by their GP or consultant. Another beneficiary who had experienced ‘low level’ digestive problems since her teens, was eventually diagnosed with persistent migraines. The medication prescribed for her migraines had also significantly improved her digestive problems.

Rightly or wrongly, some participants suspected that their bowel and digestive problems might be related to unrecognised internal damage caused by Thalidomide. The quotations below illustrate this:

*“Your brain kind of wondered always whether it is related or not. You know, as you get older your hearing starts to go a little bit and your eyesight starts to go a little bit. Well is that just aging...well it probably is just because I’m fifty-odd but you always kind of wonder because I know other people did have their hearing and eyesight and various internal organs affected by it...and when you’re a child, when we were all assessed, because the damage to ones hands and arms was so obvious, I presume they never checked for anything else. I remember being assessed as a small child but I think it was just external”. (Interviewee 2)*

*“Not a specific diagnosis as the cause appears unknown or at least not sufficiently mainstream/textbook for my GP to have a definitive answer. My guess - internal abnormalities of the digestive tract caused directly by long standing original damage from Thalidomide which are now demonstrating themselves increasingly as I age”. (Survey Respondent 10)*

## **5. Practical and Psychological Impact**

The survey responses and interviews highlighted the enormous impact that bladder and bowel problems are having on beneficiaries’ day to day lives and mental wellbeing. As a minimum, many participants had had to change their daily routine, for example not leaving the house in the morning until they had been to the toilet and only eating or drinking at very set times. For a few, bladder and bowel problems had been a factor in them giving up work or changing their jobs. One participant, who is four limb effected, explained that he dislikes having to go to the toilet at work because it take him about 20 minutes to undress and dress but he doesn’t want to get dehydrated:

*“I’ll drink water first thing in the morning, like a pint or so of water and I know that will then make me go two or three times before I leave the house and then I’m usually ok until later in the day”. (Interviewee 6)*

Several explained that if they had a day when (in particular) their bowel problems were bad they were often unable to leave the house, or had to delay going out for a few hours until they had been to the toilet several times. For some this was because they felt unwell. One beneficiary said *“Some days I can’t leave house as I feel very tired and I think it is due to this problem [IBS]”* (Survey Respondent 7), whilst another explained - *“The main problem I have is that I only have a short period of time from feeling the need to go to actually getting to a toilet. Delaying would mean that I get severe painful cramps that leave me unable to walk”*. (Survey Respondent 6). However, for those who were upper limb or upper and lower limb affected, it was the very practical issue of getting to the toilet and undressing in time to avoid *“an accident”*. It was also clear that several beneficiaries were finding it increasingly difficult, physically, to go the toilet independently, which had huge practical implications as the quotations below illustrate:

*“When I was younger I was more agile and going to the bathroom for a bowel movement wasn’t a big deal. You could get everything off. Whereas now I get nervous about it and that makes me want to go even more”*. (Interviewee 6)

*“I used to use an aid to get myself to the loo, to undo the zip and everything but that became increasingly that became more and more difficult as my body stiffened up, to the point where I needed help. I had to use a unisex disabled toilet so that my female assistant could help me with my trousers and stuff. That’s quite restricting lifestyle wise”*. (Interviewee 1).

*“A big impact as I can’t manage to go to the toilet on my own and as the irritable bowel can just pounce on me I daren’t go out on my own”*. (Survey Respondent 5)

Even for those people who could still go to the toilet without help some or all of the time, bladder and/or bowel problems are affecting their daily lives. Several people said that when they left the house they were always worried about where the toilets were. Others explained that if they went out socially they often had to come home early to go to the toilet, or only went to friends or places where they knew they could use the toilet. For some male beneficiaries, the need to wear smarter clothes for work or simply wanting to look smart when going out socially created problems. Trousers with zips and button were difficult to fasten and unfasten but they disliked having to wear elasticated ‘jogging type’ trousers. Several said that whilst they did still travel, it was now more difficult. A few explained that if they did have a problem getting to the toilet in time, they needed assistance to clean themselves:

*“If she [wife] isn’t there I have to do it myself and sometimes it has been embarrassing, if I’ve been at a show or something and I haven’t quite cleaned it right and you’ve no way of washing it I just have to go back to the hotel and start again. It doesn’t happen every day but it does happen. It’s embarrassing but you have to deal with it”*. (Interviewee 3)

*“Never stray too far from the toilet in the mornings or evenings but this is difficult when away from home. Need help to clean up after a leakage has occurred, although I have a closo-mat, often need to be completely washed down. Makes going out very difficult...”* (Survey Respondent 3)

Almost without exception, participants noted how psychologically distressing bladder and bowel problems were and how they had affected their general wellbeing. There was the obvious distress caused by not getting to the toilet in time - *“There was the odd time when I was unable to, shall we say ‘contain it’, and it’s very distressing. You feel like a bloody child. It’s awful”* (Interviewee 1). However, others said that these problems (and the consequences of them such as having to use pads, leaks and odours etc.) had significantly affected their confidence. For some it was the sense of losing another bit of their independence:

*“My weight yoyos...I find that if my stomach gets bigger bending becomes a problem and my wife has to be there to help. I’m very much a man’s man, I really am...and the type of working environment I’ve always worked in has been with men’s men. The older I’m getting, even psychologically, I would say I’m finding it very difficult because I’ve always been a very independent person as well and now I’m relying more on my wife”.* (Interviewee 7)

Several participants, especially those with bladder problems, experienced disrupted sleep, which was affecting their physical and mental wellbeing – *“The bladder problem means I sometimes have to spend quite a long time in the loo, which is particularly distressing in the middle of the night, as I can’t get back to sleep”* (Survey Respondent 2). A few participants mentioned that they were unable to take pain medication because it either upset their stomach or caused problems with constipation. Given the number of beneficiaries reporting musculoskeletal problems and/or chronic pain, this is a concern. Lastly, as has already been noted, participants had concerns about the short and long term health implication of dehydration.

## 6. Self-Management

Participants had taken various steps to self-manage their bladder and bowel problems. As Table 3 below shows, the most common amongst survey respondents was changes to diet. This was also the case for the interview group but they also described other changes in their eating and drinking habits such as not eating after 6pm or eating at very regular intervals.

**Table 3 Self-management approaches**

Steps taken to manage problems	Number of Respondents	%
Changing my diet	11	61%
Doing exercises	4	22%
Doing bladder training	6	33%
Taking over the counter medication	7	39%
Changing my daily routine	3	17%
Making changes to my home	1	6%

Many beneficiaries who had changed their diet appears to have done this through a process of trial and error, alongside internet research and reading or talking to other Thalidomide survivors. Some

had adopted a gluten free diet or had cut out certain food that appeared to ‘trigger’ problems. Several said that they had reduced or cut out alcohol and caffeine. A few had had dietary advice from a health professional, usually their GP or consultant but two had seen a dietician. One interviewee had sought help from a dietician to move to the low FODMAP diet<sup>4</sup> for the management of IBS. The diet (which has research evidence behind it) involves identifying sensitivity to different groups of carbohydrates, and then cutting out the foods that contain them. Keeping to this diet had largely got rid of his IBS symptoms.

As was noted earlier, some people had found exercises and bladder training helpful. A high proportion of those with bowel and digestive problems had tried over the counter medication but with mixed success and at some cost. For example, one participant was using Gaviscon which is not on prescription and estimated that it was costing him around £70 per month. Others said that losing weight or managing their weight, and doing regular exercise had helped. Lastly a few people said that they had recently installed or had for some years used a clos-o-mat or Geberit toilet. However, the quote below sums up the growing need to advice and support:

*“I wonder whether diet changes may help the digestive issue but am not sure how to get advice on this. I tend to use the toilet as infrequently as possible (bowels) because it takes so long. I have thought about installing a clos-o-mat toilet but am fearful that becoming dependant on one at home will limit my freedom of movement outside the house”.* (Survey Respondent 9)

## 7. Support from the Trust

In both the survey and the telephone interviews, participants were asked about what the Trust might do to improve support for beneficiaries who are experiencing bladder and continence and/or bowel and digestive problems. The value of simply knowing that other beneficiaries were experiencing similar problems and the desire to share both problems and solutions came out particularly strongly in this piece of research, as the quotations below highlight:

*“It would have made a difference if you sort of knew that other people were going through similar issues. Just having that information. Sometimes someone else is dealing with it in a different way to you and that information helps. It might not be exactly what you need. It might be an idea or thought that you can adapt to meet your needs”.* (Interviewee 6)

*“Comparing notes with another Thalidomider with similar problems has been useful and I didn't feel so alone”.* (Survey Respondent 1)

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<sup>4</sup> FODMAP stands for fermentable **o**ligosaccharides, **d**isaccharides, **m**onosaccharides and **p**olyols, which are more commonly known as carbohydrates. These can be further divided into five groups called fructans, galacto-oligosaccharides, lactose, excess fructose and polyols. The diet originated in Australia and has been adapted for the UK by researchers at Kings College, London. In essence, FODMAPs are different carbohydrates found in a wide range of foods. These sugars are poorly absorbed and pass through the small intestine and enter the colon, where they are fermented by bacteria. Gas is then produced, which stretches the sensitive bowel causing bloating, wind and pain. This can also cause water to move into and out of the colon, causing diarrhoea, constipation or a combination of both. People with IBS are more susceptible to the problems that are associated with this.

*“Knowing that I'm not the only one has helped loads”.* (Survey respondent 12)

More generally, many of the ideas and suggestions put forward were similar to those raised in the research into falls and balance problems. These are set out below:

**Information** – Making available information about the types of bladder and continence and/or bowel and digestive problems Thalidomide survivors are experiencing was seen as very important. However, participants also felt the Trust should bring together information about possible causes, treatment options and self-management strategies.

**Peer to peer support** – As was noted above, participants highlighted the value of sharing experiences and information with other Thalidomide survivors. They supported the idea of a ‘discussion forum’ in the beneficiaries’ only section of the website and felt that it might be particularly valuable for discussing sensitive topic like bladder and bowel problems.

**Access to specialist healthcare practitioners** - Those participants who had struggled to get a diagnosis or effective treatment wanted the option of being referred to a specialist with a least some knowledge of Thalidomide damage, in particular a urologist and/or a gastroenterologist. Others felt there would be value in the Trust holding details of, or at least advising beneficiaries on, how to get access to continence nurses, physiotherapists specialising in continence problems and dieticians who could help with special diets for conditions such as IBS.

**Possible link between bladder/bowel problems and Thalidomide damage** – anecdotal evidence suggests that some conditions such as IBS (or IBS symptoms) and acid reflux may be more common amongst Thalidomide survivors. As data collection on the health issues faced by beneficiaries further improves (for example capturing data from HNAs) we will have a clearer picture of whether this is the case. However, a few participants felt there would be value in a specific piece of research to establish whether this was the case – *“To understand if it is linked to Thalidomide and if so how we can best help ourselves as well as medication and/or surgery”* (Survey Respondent 5).