

The **Thalidomide** Trust

Falls and Balance Problems Briefing Paper (Final - May 2017)

1. Introduction

For some time now there has been anecdotal evidence that, as beneficiaries grow older, falls and/or balance problems are becoming more common, and the associated fear of falling is affecting peoples' daily lives. In the 2015 Health & Wellbeing Survey, nearly a third of respondents (n=109) said they had experienced problems with falls or balance. Beneficiaries with very severe upper limb damage or mild/moderate upper and lower limb damage were most likely to report these problems, closely followed by those with severe upper limb damage or severe upper and lower limb damage. Appendix 1 provides a more detailed picture by impairment group and band. It is likely that there are a number of different causes but other than the information gathered by the Health & Wellbeing team in their work with individual beneficiaries, relatively little was known about the causes.

In light of this, the Trust commissioned a small piece of research to gain a better understanding of these problems and what might be causing them. The research also explored the impact of falls and balance problems on beneficiaries' wellbeing and independence, and the prevention and management strategies they were using to cope with falls. The findings from the research are presented in this paper, with the aim of helping the Trust look at ways to improve the support and advice it offers to beneficiaries who are experiencing these problems.

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 discussion group. The invitation to take part in the research was sent to 59 beneficiaries who reported in the Health & Wellbeing Survey that they had falls and/or balance problems and said they were happy to be contacted about further research. Twenty four people completed the survey – a response rate of 40%. Eleven beneficiaries participated in four telephone discussion groups held in late February and early March. The discussion groups were recorded and transcribed as detailed notes and quotations. The findings from both sources are brought together in this briefing paper¹.

3. Frequency, Causes and Medical Help

The frequency, nature and causes of falls appears to be changing for many beneficiaries but fewer than half had sought medical advice and none had been referred to a specialist falls service.

¹ The intention was that beneficiaries would *either* complete the survey *or* take part in a discussion group but some beneficiaries chose to do both. To avoid double counting, the figures presented in this paper are only taken from the survey.

3.1 Frequency of Falls

A third of survey respondents (33%/n=8) had experienced falls since childhood but well over half (58%/n=14) said that they started to have falls in their forties or fifties. In terms of the frequency of fall, whilst the majority (71%/n=17) of beneficiaries had had fewer than 10 falls in the last three years, seven (29%) had had 10 or more falls with two respondents reporting having 20 falls, one 30 falls and another 50 falls. The group discussions shed more light on how the experience of falls was changing. Two participants who both have a prosthetic leg, explained that they had experienced falls since childhood but felt that they were now falling more frequently - *“well I’ve always fallen because of artificial legs but as I’ve got older the recovery time has got worse and falls are getting more”* (Group Participant 1). Others said that they had only started to experience falls in the last few years. For example one said that her falls started about a year ago and since she has had a fall, on average, about every two months. Another said that most of his life he has had good balance and rarely fell but in the past three or four years he had had about eight falls and several near misses:

“I’ve noticed that I’m a lot more wobbly and I seem to lose my balance a lot more easily when I’m doing things...in the past when I’ve gone to do something where I’ve needed to stand on one leg and do it, it’s just been a natural, sort of fluent movement but I’ve noticed now that if I don’t concentrate and think what I’m going to do next, I’ll wobble all over the place and stumble to get my balance again”.

(Group Participant 4)

3.2 Causes

For around three quarters of the survey respondents (n=18) loss of balance or poor balance was a factor in their falls, and this included one respondent who was a wheelchair user. They explained that they had had a number of falls from their wheelchair due to - *“Loss of balance whilst transferring from chair to bed and visa versa [and] loss of balance on wheelchair”* (Survey Respondent 17). One participant explained that she had otitis (narrow ear canals - a common aspect of Thalidomide damage) and when her ears became blocked her balance deteriorated. Seventeen respondents mentioned slipping or tripping and many talked about feeling that they had lost strength in their legs or arms. A few people also noted that deteriorating eyesight was contributing to their falls. Two of the group discussion participants had specific problems with their vision, whilst others were simply coping with normal changes in eyesight associated with ageing. Six beneficiaries described their falls as *“unexplained”*. One beneficiary described what happened to him - *“It’s like one minute I’m walking along then the next I’ve lost my balance and I’ve gone. I can’t even say I’ve tripped over something”* (Group Participant 4). For many people there appeared to be more than one thing contributing to them falling, as these quotations illustrate:

“Changed walking pattern due to trapped nerve in spine”. (Survey Respondent 3)

“Balance, deterioration of eyesight, back problems, and my legs have given way a couple of times”. (Survey Respondent 20)

“Balance problems, right ankle problems and problems with prosthetic limbs”. (Survey Respondent 24)

Perhaps not surprisingly, several beneficiaries said that environmental factors such as uneven ground, slippery surfaces and steps or stairs had often contributed to them falling. Many also felt more at risk of falling in poor weather, at night and when in an unfamiliar place. However, a few said falls could happen at any time and anywhere.

“The falls just happen...its worse when I’m tired or have been standing for a long time or doing something arduous...if I’m tired I have to be really careful as it just hits. One minute I’m ok and the next minute it’s ‘whoa’”. (Group Participant 1)

3.3 GPs Consultations and Investigations

Eleven survey respondents (45%) had consulted their GP about falls or balance problems. The group discussions revealed that often people were reluctant to go to their GP because they felt that they wouldn’t understand the implications of their Thalidomide damage in relation to falls and/or they felt nothing could be done. A few participants who had consulted their GP did report these problems. However, others had been referred for treatment or investigations. Six survey respondents had had physiotherapy and three had been referred to a hospital consultant - two to orthopaedic surgeons and one to a neurologist. In addition, one respondent said they had been referred to a pain clinic and one of the discussion group participants (who did not complete the survey), had been referred to an ENT specialist. Interestingly, no one had been referred to a falls clinic or falls service.

Fourteen survey respondents had had tests or investigations to better understand what might be causing the falls or balance problems they were experiencing. Mostly these had been arranged by their GP but some people had arranged things like eye tests themselves. Table 1 below shows the investigations that respondents had had.

Table 1 Investigations

| Test/Investigation | Number of Respondents | % |
|---------------------------|-----------------------|-----|
| Blood pressure monitoring | 5 | 21% |
| X-rays | 6 | 25% |
| MRI or other scans | 5 | 21% |
| Eye tests | 4 | 17% |
| Ear/balance tests | 1 | 4% |
| Medication review | 3 | 12% |

Together the survey responses and the group discussions suggest that the root causes of falls varied and were often multiple. However, loss of flexibility/agility due to secondary muscular skeletal damage and deteriorating balance were clearly significant for many beneficiaries, and changing eyesight was contributing factor for some. There was also a small group who had what appear to be unexplained falls but the group discussions and comments added to the survey (e.g. *“failing knees”*)

and “arthritis in feet, knees and lower back”) suggests that these might also be partially caused by secondary muscular skeletal damage.

4. Consequences of Falls and Balance Problems

Whilst falls had an obvious physical impact on people, it was often the wider psychological and social consequences that had the most serious effect on beneficiaries’ lives. Both these aspects are discussed below.

4.1 Physical Injuries

Most of those who contributed to the research had experienced cuts, bruises, painful or pulled muscles and/or damage to ligaments. However, a third (n=8) had reported having fractures as a results of a fall and these included fractures to vertebrae, hips, knees, ankles, arms, ribs and collar bones. Three people had experienced concussion and several people had injured their faces, including broken noses, black eyes and broken teeth. A few people said they had experienced breathing difficulties after a fall, including one who had sustained a punctured lung. These physical injuries often had longer term implications, ranging from a prolonged period in hospital, lengthy rehabilitation, being unable to drive for several weeks and semi-permanent loss of function. The two quotations below illustrate this:

“Badly damaged ankle ligament, treated as a fracture, with a weight-bearing cast and crutches, followed by several months of physio and walking with a stick. Seven months in all. I still can’t use stairs without using a hand rail”. (Survey Respondent 4)

“Broken teeth, which has led to loss of independence in dressing, carrying things, lifting briefcase and books”. (Survey Respondent 17)

4.2 Psychological and Social Consequences

Both the survey responses and the group discussions highlighted just how much falls and/or the fear of falling was affecting beneficiaries’ independence and general wellbeing. Previous work with beneficiaries had suggested that there were seven areas where falls or the fear of falling often had a significant affect, and so the survey specifically asked about these (see Table 2 below).

Table 2 How falls or the fear of falls affected people

| | Number of respondents | % |
|--|-----------------------|-----|
| Feeling more vulnerable | 21 | 88% |
| Feeling embarrassed about falling | 20 | 83% |
| Feeling less confident about things in general | 17 | 71% |
| Being less active outdoors | 13 | 54% |
| Needing more support/help with activities | 11 | 46% |
| Having to make changes to your home/garden | 9 | 38% |
| Going out socially less often | 7 | 29% |

As these results show, falls often left people feeling more vulnerable and had a detrimental effect on their confidence.

“They have certainly affected my confidence which then impedes daily life. I can't remember the last time I went out alone unless I was driving and going to visit friends or family”.

(Survey Respondent 6)

For some people these psychological consequences were very significant and even life limiting. Several participants explained that they avoided going out in the dark or in bad weather or didn't go out alone or were very selective about where they went and many noted that they were increasingly reliant on their partners, family or PAs to support them when they went out. One discussion group participant said that she has started to “map” everywhere she goes to anticipate problems or obstacles. The quotations below bring these issues to life:

“My fall has left me with loss of confidence and since then I suffer from extreme anxiety and always terrified of falling. I try to avoid certain areas that I feel may contribute to falling i.e. stairs, escalators, cobble stones etc.”. (Survey Respondent 12)

“It's the fear of going out, especially when it gets dark and alone, in case you do fall because any uneven surface and you can easily trip...it's very binding because you've got that fear in your head – ‘what will happen if I go out and I have a fall’ so you're tense all the time when you go out and that's no fun you know...it's like robbing your life”. (Group Participant 2)

Several participants explained that whilst they had tried not to let the fear of falling limit their lives, they had made changes. For example one participant who lives near the coast and enjoys walking, no longer feels safe going walking alone on the beach. Another said that she taken the decision to stop using steps and ladders because the implications of falling from a height were just too serious - *“You get to a point of thinking I'm not going to risk climbing on something or going somewhere because if I fall the resulting injury might mean that my abilities are reduced, plus you just get more fearful of falling. You know you don't bounce back and a fall really takes it out of you”* (Group Participant 6). A number of beneficiaries who use their feet for everyday tasks said that balance problems were now limiting what they could do both in the home and when out and about:

“The problems have taken some of my confidence away...It's silly things like you stand to pay with a credit card but I'm standing on my bad leg and of course the machine is always at hand height, you know waist height and I'm standing on my bad leg trying to press buttons. So that's not very safe”. (Group Participant 11)

Lastly, in the group discussions, it became clear that some beneficiaries were unaware that others were also experiencing falls and balance problems. They found it reassuring to know they were ‘not alone’ and several participant shared advice about regaining confidence and strategies for preventing falls.

5. Prevention, Solutions and Support

Beneficiaries were very aware of the both the physical and psychological consequences of falls and were taking active steps to either reduce the risk of falling or coping when they did fall. They also had a number of suggestions for how the Trust could help.

5.1 Preventing Falls

The survey confirmed that many beneficiaries had taken steps to reduce the risk of falling - only two respondents said they had done nothing. As Table 3 below shows, the two most common steps were doing exercises to strengthen legs and/or improve balance. Other practical steps that people had taken included: using of a mobility scooter for trips outside the home; getting out of bed more slowly; getting assistance on stairs; and choosing shoes with good grip soles. Of the two discussion group participants who had specific problems with their vision, one explained that she now always wears her new glasses (which correct the sight problem) and the other said that when she starts to experience the problem with her sight (colours in her eyes) she knows to slow down and be extra careful.

Table 3 Steps taken to reduce the risk of falling

| Steps taken | No of respondents |
|--|-------------------|
| Doing exercises to strengthen legs | 14 |
| Doing exercises to improve balance | 14 |
| Learning to fall 'safely' | 6 |
| Using a walking stick or other walking aid | 3 |
| Using prosthetic limb less/wheelchair more | 2 |

A number of survey respondents said that they had taken up Pilates with the aim of both improving their balance and increasing their 'core' strength. The group discussions revealed how Pilates was benefiting some beneficiaries. One participant explained that through a combination of weight loss and Pilates she was able to stand for longer periods without feeling unsteady, and could get up off the ground more easily. Another said that she has one to one sessions with her Pilates instructor and this had greatly improved her balance.

5.2 Falling Safely and Getting Up

A number of the group discussion participants, especially those who were upper limb affected, explained that as children they had developed ways of falling to protect themselves but increasingly they found that these approaches didn't work or physically they could no longer use them.

"I was bendy girl. I could bend in any direction and I could just fall in a gentle flop but we can't fall gently any more. We go like a big bang. I can't let my knees drop and my hips drop as I would have done before...you don't fall the same way". (Group Participant 11)

“When I was a child and a young adult my method was lead back and fall on your bottom but I find when I’m going to fall now, I’m already somehow leaning forward and I can’t pull myself back from the forward projection. I would say that is the biggest difference in trying to save yourself”. (Group Participant 10)

Several upper limb affected beneficiaries explained that a further problem was getting up off the ground if they did fall, especially if they were on open ground and had nothing on which to pull themselves up. The quotations below illustrate this:

“I’ve played football all my days and I used to go into tackles...I broke two shoulders playing football but because I could get back up it was no problem to me but now this is my knee. I’ve actually done my other knee a long long time ago and that was playing football but I always had the other knee to get up on but now my two knees are shot”. (Group Participant 7)

“If I fall, I am unable to get up unless there is something to crawl up. That makes me feel very vulnerable outside of the house unless I am with someone who can pick me up. Passers-by don't know how to pick me up from the floor and even if I instruct them on how to help me up safely, they are worried about hurting me by pulling on my arms”. (Survey Respondent 13)

One beneficiary who is from an Asian background explained that she grew up sitting on the floor but now if she gets down she can’t get up unless there something she can lean on. From a cultural point of view, this can be a little awkward when she goes to the temple or visits family.

5.3 Personal Independence Payments

Falls can be taken into account in assessments for Personal Independence Payments (PIPs) and so the survey asked respondents whether they were in receipt of a PIP. Eleven beneficiaries (46%) said they were and of these five got the enhanced mobility rate and two the standard rate (two did not provide this information). Two respondents noted that they had recently had a PIP assessment. In their assessments, one had raised the problem of deteriorating balance and unexplained falls. The other said that she had been asked if she could walk 200 yards, and had explained that whilst she could, the risk of fall was high because of problems with her prosthetic limb.

5.4 Support from the Trust

In both the survey and the group discussions, participants were asked about what the Trust might do to improve support for beneficiaries who are experiencing falls and balance problems. The suggestions they put forward are set out below:

Information about falls and balance problems – Simply providing information about falls and balance problems amongst thalidomide survivors was seen as an important first step. Three key topics were highlighted:

- Information for beneficiaries about the prevalence of falls and balance problems; the most common or likely causes (e.g. musculoskeletal problems, changes in vision, otitis etc.); and the importance of seeking medical advice and/or having tests, where the cause of falls isn't clear
- Information for GPs about the nature and implications of falls and balance problems for Thalidomide survivors and why tests and investigations may be needed to fully understand what is causing them
- Advice about reducing the risk of (and coping with) falls, ranging from practical steps for everyday life (e.g. always carrying a mobile phone, suitable walking aids) to exercises to strengthen the legs and core, and improve balance. The Trust has recently commissioned two films about Pilates (one for Pilates teachers and one for beneficiaries) but it was felt that a series of short films (ideally involving beneficiaries) about strengthening exercises and techniques for getting up of the ground for Thalidomide survivors with different types of damage would also be valuable

Peer to peer support – As in the discussions about access to healthcare services, participants highlighted the value of sharing experiences and information with other Thalidomide survivors. They supported the idea of the Trust doing even more to facilitate information sharing and peer to peer support, and the proposal for a 'discussion forum' in the beneficiaries' only section of the new website was again put forward. Participants felt this would provide a safe place to exchange tips on how to reduce the risk of a fall. Peer to peer support was also seen as a potentially important way of helping people regain their confidence after a fall. In particular participants thought there might be scope for webinars on specific topics and facilitated phone support groups, which could perhaps link people who had had similar experiences.

Access to a specialist assessment – It was suggested that for a few people, especially those with unexplained falls, it would be helpful to have access to a more specialist and comprehensive assess than was routinely available in local NHS services

Practical training sessions – The participants who had attended Fit for the Future said that the session about techniques for getting up of the ground had proved very popular and useful, and that splitting people up into groups with similar damage had worked well. There was agreement that more practical sessions of this type, perhaps also covering ways of falling 'safely' would be very valuable

More bespoke prosthetic services – The two participants who used prosthetic legs raised concerns about the quality of NHS prosthetic services, an issue that also arose in the access to health services work. As one of them put it - *"we need a bespoke service because each one of us is different. We are not just a through the knee amputee, we've got everything else messed up above it. So we need a bespoke service and they are offering off the peg"*.

List of physiotherapist with Thalidomide experience – Whilst many beneficiaries see private physios and complementary therapists, some are reluctant to use these practitioners unless they know they have some knowledge or understanding of Thalidomide damage. One suggestion was that the Trust could maintain a list of such practitioners in different regions of the UK, who have experience of treating Thalidomide survivors

Appendix 1 - Falls and Balance Problems by Impairment Group and Band

Table A1 Number/Proportion of Health & Wellbeing Survey Respondents Reporting Falls/Balance Problems

| Impairment Group | Band 1 | Band 2 | Band 3 | Band 4 | Band 5 | Band not known | n= (%) in group reporting falls/balance problems |
|--|----------------|-----------------|-----------------|-----------------|-----------------|-----------------|--|
| Upper limb very severe | | | 12 | 8 | 1 | 2 | 23 (44%) |
| Upper & Lower limb mild | 1 | 1 | 9 | 1 | | 5 | 17 (44%) |
| Upper & Lower limb severe | | | | 11 | 5 | 2 | 18 (36%) |
| Upper limb severe | | 4 | 9 | 2 | 1 | 5 | 21 (34%) |
| Lower limb only | | 1 | | 1 | 1 | 1 | 4 (29%) |
| No limb damage | | 2 | 6 | | 1 | 2 | 11 (26%) |
| Upper limb mild | 2 | | | 1 | 1 | | 4 (17%) |
| Upper limb moderate | 2 | 7 | 1 | | | 1 | 11 (16%) |
| n= (%) by band reporting falls/balance problems | 5 (15%) | 15 (19%) | 37 (37%) | 24 (48%) | 10 (25%) | 18 (37%) | 109 (31%) |

Figure A1 Proportion of Survey Respondents Reporting Falls/Balance Problems

