

The **Thalidomide** Trust

Healthcare Services – Access, Quality and Improving the Care Pathway for Thalidomide Survivors

1. Introduction

The work of the Health & Wellbeing team and the evaluation of the Health Grant have clearly shown that routine NHS services often struggle to provide appropriate diagnosis, treatment and care for Thalidomide survivors. This was confirmed by the Health and Wellbeing survey, which found that (in the past five years) nearly two thirds of beneficiaries had experienced one or more problems with the quality of and/or access to health services. Half perceived a lack of knowledge or understanding of Thalidomide damage amongst healthcare practitioners and a third felt they lacked knowledge or understanding of their particular impairments. The other major area of concern was difficulties or delays in seeing a healthcare professional with the necessary experience and knowledge.

The Health & Wellbeing Survey was sent to all 467 beneficiaries and achieved a 75% response rate; respondents were representative of the whole Thalidomide community in terms of gender, the severity of their impairments and their country of residence. In the original survey 215 respondents (61%) said that (in the last five years) they had experienced one or more problems with the quality of and/or access to health services. Of these, 170 (48%) respondents reported a perceived lack of knowledge/understanding of Thalidomide damage in general amongst health professionals; 127 (36%) reported a perceived lack of knowledge/understanding of their specific impairments amongst health professionals and 81 (23%) respondents reported difficulties/delays in seeing a suitably experienced health professional/specialist, with a similar number reporting delays in getting treatment (82/23%).

Importantly, a small number had experienced misdiagnoses or delayed diagnoses (48/14%) and a similar number reported being given incorrect or inappropriate treatment (47/13%).

More encouragingly, 193 respondents (55%) felt that their GP fully understood or partly understood how their Thalidomide damage affected them and almost half (45%) thought that if they had a Thalidomide-related health problem their GP would be willing to seek advice from a specialist with knowledge of Thalidomide damage and/or from the Trust. However, a similar number said they were not sure/did not know and 23 respondents (7%) felt that their GP would not be willing to seek such advice.

The findings of the Health & Wellbeing survey in respect of beneficiaries' concerns over access to appropriate healthcare are supported by the growth in enquiries to the Health and Wellbeing team within the Trust from beneficiaries seeking help with obtaining the healthcare they needed. . In 2016 the Trust's Medical Advisor was involved in supporting 77 beneficiaries to obtain access to appropriate health care services and has already dealt with 50 such contacts since the beginning of 2017. Demand for access to consultants with knowledge of treating people with Thalidomide damage, through the Trust's private referral scheme has increased significantly in the last 12 months. As the support available to beneficiaries from the Health and Wellbeing team becomes more widely understood, we expect these numbers to continue to grow.

As more Thalidomide survivors develop secondary health problems and/or report difficulty managing other health problems associated with age and lifestyle, their need for health care services will increase. Moreover, they will have a growing need for healthcare practitioners who understand the implications of Thalidomide damage, and have the knowledge and experience to diagnose and treat Thalidomide survivors effectively. So, as part of the follow-on work from the H&W survey, the

Trust decided to explore beneficiaries' experiences of healthcare services in more depth, and to seek ideas for improving the 'pathway of care'.

2. Approach

The initial plan was to discuss these topics in two focus groups (in different locations), each with around six to eight beneficiaries. Unfortunately, it was only possible to run one group (of four beneficiaries) in Manchester but five other beneficiaries agreed to take part in one to one interviews (one face to face and four by telephone). Of the nine beneficiaries who took part: two were men and seven were women; eight lived in England and one in Northern Ireland; three were in impairment band 2, four in band 3, one was in band 4 and one in band 5. One participant had upper and lower limb damage, six had upper limb damage only, one had lower limb damage only, and one participant was deaf.

Clearly, with just nine participants, it is important to interpret the findings with caution. Nevertheless, their experiences do illustrate the issues highlighted in the Health and Wellbeing survey, in particular the impact of poor care and the benefits of good care. Importantly, the discussions did generate a number of ideas which the Trust may wish to consider further.

3. Experiences along the Pathway of Care

3.1 Primary Care and Referral Processes

Most participants said the GPs in their practice had only limited knowledge of their Thalidomide damage but were generally willing to try and understand. However, they also noted that GP practices are now very busy and that sometimes, even in a double appointment, there did not seem to be enough time to discuss their health problems properly. This problem is often compounded by a lack of continuity. Several participants said they frequently see a different GP at each appointment, or have to wait a long time to see their preferred GP. Clearly these pressures affect all patients, not just Thalidomide survivors but it is perhaps more problematic for patients with disabilities or more complex needs. One participant explained that he always books a double appointment but, because his Thalidomide damage is severe, when he sees a GP who doesn't know him, the GP might spend several minutes reading his notes which then reduces the consultation time. Others noted that just doing things like removing items of clothing or getting on and off the examination couch took them longer, and so they often felt rushed during appointments

Two participants felt that their GPs were particularly good. One noted that her GP really listened to her and recognised her knowledge of her own body. The other participant said his GP acknowledged that he knew very little about Thalidomide damage and had taken time to talk to the Trust and ensure that he was referring to the right specialists.

"My GP is excellent. He says 'I don't know and I'm quite happy to refer you'. There is no ego with him – he doesn't feel anyone is telling him his job. He'll phone Dr Dee at the Trust and say 'where do I need to send him, what do we need to do' (Participant 4)

By contrast three participants had had major problems with GPs, all of which resulted in them not getting the specialist diagnosis or care they needed, which in turn had implications for their general wellbeing.

Personal Story (Participant 9)

M explained that the GP service in her area is generally poor but because of her disability this had particular implications for her. Two serious and prolonged periods of illness meant that she was housebound for several months. During the first illness, her GP never came to see her, despite her needing significant pain control medication. As a result she felt she endured unnecessary pain, which was distressing for her and her family. After the second period of poor health, she requested physiotherapy in order to try and regain as much function and mobility as possible but he refused to refer her. She felt a sense of being 'written off' and of her wish to regain her function and independence being seen as somehow less important because of her disability.

Personal Story (Participant 2):

A GP at A's surgery assumed he knew about Thalidomide damage and refused to accept that A, who has no limb damage, was a Thalidomide survivor. A obtained a letter from the Trust explaining that she was a Thalidomide survivor and requesting a referral to a specialist in London, who could investigate her particular muscle and 'nerve' pain. She explained:

"I booked an appointment with the GP and he read the letter. Then he looked at me and said 'there is nothing wrong with your body, your limbs are fine' so he dismissed the piece of paper and turned to me and said let me ask you some questions, 'how many months did your mum take the tablets for when she was pregnant?' I said, 'hang on a minute, I didn't come here to talk about that, I came here for you to refer me so why are you still ignoring me?' and he said 'well you look quite normal to me, are you sure you are Thalidomide?' I just welled up... I got up, walked out, slammed the door and burst into tears."

Despite further intervention by the Trust, and another appointment, the GP did not make the referral to the specialist and simply sent A for a short course of physiotherapy which had no effect. A said that she felt very dispirited by the whole experience. She has given up trying to get a referral to a specialist and now relies on prescription medication to control her pain.

Personal Story (Participant 6)

F had experienced several unexplained falls. Initially her GP thought they may be related to a problem with her blood pressure. Unfortunately, because of her (upper limb) Thalidomide damage, the home blood pressure monitoring device she was given could not take accurate readings, and the GP did not offer an alternative. After another two months, another fall, and increasing pain in her hips and knees, she went back to her GP and asked if she could have her hips and knees x-rayed to see if damage to those joints might be contributing to her falling. The GP asked her *"can you walk on them...can you suffer it [the pain]?"* and when she said she could cope with it he declined to refer her. She still does not know what is causing her to fall and having been an active person all her life, she now feels she is losing the confidence to walk outside on her own.

It is likely that this reluctance to refer on to specialists or for investigations is partly the result of the financial constraints in the NHS and GPs feeling under pressure to reduce referrals and investigations. Again, this may affect any patient but the consequence for Thalidomide survivors can be particularly serious, because compared to people of a similar age, they are more likely to require a specialist referral, more likely to need investigations and more likely to lose function and mobility if their needs are not addressed.

3.2 Monitoring, Diagnosis and Screening

The Trust is already very much aware of the problems that many beneficiaries (especially those who are upper limb affected) experience in obtaining an accurate blood pressure measurement. Several participants described the problems they had encountered. Sometimes this was simply a lack of understanding or insensitive care. As one beneficiary explained:

“They look at you as if they don’t know what to do with you...when I have my blood pressure taken they say ‘straighten your arm’ and I say ‘it’s as straight as it goes’ and then its ‘can’t you straighten it a bit more’. It’s a bit unfeeling.” (Participant 1)

For some, not being able to obtain an accurate blood pressure measurement meant their health problem was not properly investigated, as was the case with the beneficiary in Personal Story 3 above, who had experienced unexplained falls. For others it simply meant that the kind of routine monitoring that most patients receive (e.g. through Well Woman clinics or NHS Health Checks) was not available or was less comprehensive – *“I’ve got no idea if I’ve got high blood pressure or not because it’s different, the reading is different every time it’s taken. So, I’m none the wiser.”* (Participant 7)

There were also examples of innovative solutions. One beneficiary explained that during a recent planned admission to hospital, the staff used a cuff designed for babies and linked it to a digital blood pressure monitor. In this way they managed to obtain reasonably reliable readings, but he noted that most adult healthcare services don’t have access to baby cuffs. Participants welcomed the Trust’s efforts to commission clinical research into alternative and better ways to measure blood pressure. However, only two were aware of the information about taking blood pressure (in the leg) available on the Trust’s website.

The other issue raised by all except one participant was the difficulties experienced when having a blood sample taken. For many this was a painful and sometimes distressing procedure. Healthcare professional frequently failed to appreciate the potential difficulties and often did not listen to beneficiaries when they tried to explain the best places to try and take a blood sample. The quotations below vividly illustrate these experiences:

“I had a lady taking blood and I only have one place in one particular vein and the needle has to go in at a certain angle. If it moves there’s nothing...I was going to have some surgery and I said this is the place but she said ‘no, no I’m going to try here and here – I know my job’. Then she said we’re going to put you under anaesthetic and then I’ll take the blood. I woke up and there were about 11 little round plasters on my legs where she’d tried.” (Participant 4)

“I do have an area that I do point people in the general direction of but it doesn’t always work, no. Well, it very rarely works like that. They’ll stick the needle in and some people will start rummaging around and moving the needle around while it’s in your arm, and that is awful, while they’re trying to find a vein. And I end up feeling all faint and sick and horrible. It’s an unpleasant experience, I must admit, and I’d rather stay clear of it really.” (Participant 7)

As a consequence of these problems, several participants said that they try to avoid having blood tests, even when this was necessary for monitoring a long term condition such as diabetes or under/over active thyroid. However, here again there were examples of good care and innovative approaches to the problem. One participant, who needed regular blood tests, said that she had built up a good relationship with one the nurses in her GP practice and between them they had found a solution - she used a butterfly needle designed for children. This beneficiary had one vein in the back

of one hand where it was easier to get blood. The nurse was aware of this and always used that place. Another participant who also need regular blood tests but found giving a blood sample very painful, explained that his GP now referred him to his local hospital. The phlebotomist there was very skilled and usually managed to get a sample relatively painlessly. Others described healthcare practitioners using anaesthetic spray to numb the arm before putting the needle in.

Finding a vein for an anaesthetic prior to an operation or for inserting a cannula after an operation was also a problem for many. Several beneficiaries said that when they had been in hospital for an operation, they had asked the anaesthetists to 'put them under' with gas first and then find a vein. Another described how ahead of a major operation the surgeon had talked to her about where he should put the cannula. However, other participants had had bad experiences, for example waking up with cannulas in their neck or feet, without any prior discussion.

Again the Trust is very much aware of these issue and has produced a leaflet for beneficiaries, *Giving Blood More Easily*, and a letter they can give to their GP. However, most participants were unaware of the leaflet and letter. Three participants had used the vein viewer and had found it helpful. However, they noted that it is really only helpful for planned appointments, where there is time for the Trust to send the viewer to the beneficiary.

As was discussed in 3.1, a number of participants had experienced difficulties getting their GP to refer them for diagnostic tests/imaging, especially x-rays and MRI scans. It is difficult to know the reason for this but alongside financial constraints, participants suggested that it was in part rooted in a lack of understanding of the 'hidden' nature of some Thalidomide damage. They often felt frustrated because without this information they couldn't get the treatment they needed.

"I mean, when I had the X-rays of my knees, I sort of pushed to have an MRI scan, because I haven't had that and with my bones, I'd quite like to know what's going on. But the GP didn't want to do that – wasn't prepared to. Obviously they cost a lot of money.... But somebody said to me 'If you have an MRI scan, they'll look at any imbalance in your hips and then you'll be referred to [local] hospital and they will work with the physios to take you back to square one, and look at your gait' – and I thought well, that's possibly what I need."
(Participant 2)

Two female participants mentioned that they had had good experiences of breast screening services. The process can take a bit longer but they both said the radiographers doing the screening had been patient and considerate.

3.3 Treatment and Care

Just as in primary care, participants felt frustrated when healthcare practitioners in secondary care didn't listen to and respect their knowledge of how Thalidomide had affected them. Two participants talked about the problems they had had with physiotherapists assuming that their shoulders joints were 'normal'. One described the attitude of the physiotherapist – *"I took my X-rays because my shoulder is a bit different and she refused to look at them – 'oh I don't need to look at those I deal with lots of shoulders'"*. Another participant, who has heart problems from birth, was taken to A&E after collapsing at home:

"The doctor said 'how long have you had your heart trouble?' I said since I was born, it is part of the Thalidomide problem, as well as not having arms and that, and he just said 'oh that won't be Thalidomide' even though he didn't know anything about Thalidomide."
(Participant 8)

By contrast, some participants said that healthcare professionals could be *too* interested in their Thalidomide damage. One participant described a doctor asking if he could bring his medical

students to see him and take photographs for 'training purposes'. Whilst this was well intentioned, it was intrusive and it made him feel like a "medical curiosity" at a time when he was already anxious.

Three participants had seen specialists for Thalidomide related secondary health problems, and all of them had been referred as part of Trust initiatives. Two of them had subsequently had treatment in hospital for musculoskeletal problems. They emphasised the importance (and relief), of being able to see a clinician with knowledge of Thalidomide damage, and preferably with experience of treating other Thalidomide survivors.

"You think, at last, I'm making some progress...You've gone from that frustration where nobody knows to suddenly somebody knows what I'm talking about and you come out and you think yes, we're going to get there". (Participant 4)

Participants very much welcomed the Trust's efforts to establish a network of specialists. One participant suggested that where a beneficiary was seeing more than one specialist (especially if they were in different hospitals) some means for sharing information and coordinating care would be valuable. Even if participants hadn't needed a specialist themselves, they found it reassuring to know that should they need one, the Trust could help them find the right one. However, they felt that this network needed to cover a greater range of medical specialties, including orthopaedics (for different joints/parts of body), neurology, cardiology, gastroenterology, and pain management. The personal story below illustrates this.

Personal Story (Participant 7)

G experienced frequent bouts of diarrhoea and pain down her left side. She saw a gastroenterologist at her local hospital and did have a colonoscopy. However, once they had established that she did not have cancer, they seemed reluctant to investigate her problems further. She explained that she didn't feel her concerns were listened to or taken seriously - *"I asked the doctor, is this connected to Thalidomide or would you find this in the general population anyway. He didn't really answer my question...and he didn't want to pursue that side of it"*. She was prescribed medication used for Irritable Bowel Syndrome but this made no difference at all. Eventually, following her own research, she moved to a gluten free diet which greatly reduced the pain but had little impact on the diarrhoea. She would have liked to see a gastroenterologist with some knowledge of Thalidomide damage, who might have been able to answer her questions about whether there was any connection with Thalidomide.

Five participants had had hospital care in the last few years. Their experiences were extremely varied. Two had been treated by specialists with links to the Trust and another by a consultant she had been seeing regularly for a number of years. None of them reported any problems. Another participant had to have surgery for a condition unrelated to his Thalidomide damage. Overall his care was good but because of complications following the operation he was taken to the Intensive Care Unit. He was placed on a special ('ripple') mattress designed to reduce the risk of pressure sores. This was normal practice but having short limbs meant that he sunk into the centre of the mattress, which made him feel sick and uncomfortable. He asked the staff to move him onto an ordinary mattress but it was only after some hours, when a senior nurse came to see him that the mattress was changed. In this situation 'normal practice' wasn't appropriate for someone with limb difference but this hadn't been thought about in advance.

The other beneficiary was admitted to hospital after breaking her hip. Whilst she noted that some of the nursing staff were very good, she had an extremely distressing experience:

“A care assistant obviously took a dislike to me and thought it would be fun to pull me down the bed by my ankles. I complained to the in-house physio and he said that she was going to damage my leg – apart from the pain. He said he would have a word with her which he did...but then I couldn’t do anything – I couldn’t walk, I couldn’t reach the emergency button, I couldn’t toilet myself, even with the bedpan – and she created a system that she would get two of her pals to stand in the hall to see if anyone was coming and then would slap me. I remember the lady opposite just crying and saying ‘why are they doing this to you’...we all felt vulnerable.” (Participant 9)

This highlights how vulnerable Thalidomide survivors can be and even beneficiaries who are generally resilient can feel unable to speak out and protect themselves when they are unwell.

None of the participants had experience of using mental health services but one participant had had counselling for PTSD. However, participants did discuss the importance of maintaining mental wellbeing. They felt that a lifetime of living with disability, coupled with more recent physical health problems, meant that Thalidomide survivors were now at greater risk of a decline in their mental wellbeing. They put forward a number of ideas for addressing this issue and these are discussed in Section 4 below.

3.4 Rehabilitation and Convalescence

Several participants highlighted the importance of access to appropriate and timely rehabilitation. Many Thalidomide survivors, like other people with disabilities, are already living with some loss of function and so regaining flexibility and mobility after an operation or injury is doubly important for them. Despite this, a few participants had encountered very negative attitudes, with doctors in particular failing to appreciate their desire to regain as much function as possible. In some cases they had paid privately for rehabilitation treatment.

The availability of specialist equipment to help with rehabilitation was also highlighted. The Trust had helped one participant to get the right equipment (a special Zimmer frame) and she felt this had made a huge difference to the speed of her recovery:

“She [H&W Coordinator] spoke to the OT at the hospital and told them what frame I needed and it was ordered. If she hadn’t done that, then I’m not sure I would be walking because the surgeon said it might be two years before you are walking again. I think part of that was because they didn’t know how they were going to get me walking again”. (Participant 9)

Convalescence care was also a concern for some participants. The NHS now discharges patients as soon as possible and whilst this is the same for everyone, it can present particular difficulties for Thalidomide survivors, especially those who live alone. Beneficiaries with upper limb damage explained that after certain types of surgery (e.g. spinal or abdominal surgery) they had felt immobilised, not being able to sit up or turn without help. On a practical level this meant that they needed a lot of extra help. However, there was also a psychological element. If everyday tasks such as washing and dressing are difficult under normal circumstances, trying to do these things when recovering from an operation or illness can feel overwhelming. One suggestion to overcome this problem, was access to convalescence facilities, with staff who had some understanding of Thalidomide damage and limb difference in particular.

Finally, one participant had a prosthetic leg and she described in some detail the changes she had seen in NHS prosthetic services. In particular she noted that the service is now extremely busy and appointments are shorter. As a consequence the fitters tend to just focus on the limb fitting aspect and rarely look at gait. At her local centre she now has to request an appointment rather than being sent an appointment at regular intervals. She recently had a new limb fitted, in part because her old

prosthetic had been made to an incorrect length and this had affected her walk and caused a number of falls. She explained that the new limb was 'off the shelf', unlike in the past when the limb fitter would take a cast of the stump and fit the limb to that. She was seriously thinking about having a prosthetic made and fitted privately but was concerned about the cost of the limb (c£30,000) and the on-going maintenance cost, as the NHS will not provide this service for privately fitted limbs. She said:

"It's not just about the quality of the limbs it's about the quality of the fitters – about the people who are looking at you and making the measurements. I mean we are never going to have perfect gaits and be symmetrical...I'm always going to have limp – that's just me but we want to be as good as we can be and we need quite a lot of detailed assessment and the time – the time they can take with you." (Participant 3)

Whilst further work is needed to understand how typical her experience is, she did highlight a number of important issues. In the Health and Wellbeing survey 36 respondents (10%) said they used a prosthetic limb/s some or all of the time which suggests that within the beneficiary community there is a sizable minority who use NHS prosthetic services.

3.5 Supported Self-Management

Many beneficiaries actively self-manage their health and wellbeing through exercise, diet and the use of complementary therapies, and they welcomed the Trust and NAC's efforts to support this. One participant had attended the Fit for the Future event and had found it very valuable. However, the discussion group and interviews also revealed that there is scope for healthcare professionals to do more to support Thalidomide survivors to self-manage. Again, this is a theme in healthcare services generally, especially in relation to long term conditions.

4. Ideas for Improving the Pathway of Care

It is part of the Trust remit to provide information, advocacy and advice on health and wellbeing issues, so that beneficiaries can maximise their health, independence and quality of life. In recent years the Trust has developed a number of initiatives to fulfil this remit. Participants provided feedback on several of these initiatives and many of the ideas that for improving the pathway of care, built on or extend them. These are briefly described below:

Health & Wellbeing team – All the participants had heard about the Health & Wellbeing service but some seemed a little unclear about what kind of help was available or how to contact the team. It is often the case that people do not take much notice of information about a service until they need it but this perhaps reinforces the need for regular communication about what Health & Wellbeing team can offer. Four participants had contacted the Health & Wellbeing team and two had had substantial help and support. All spoke very highly of the service overall and of individual members of the team. They valued being able to pick up the phone and speak to someone but also said it would be nice to be able to put faces to names. They thought the new website would be one way to do this.

Information about Thalidomide Damage and Health – The feedback from participants suggests that many beneficiaries are unaware of the information on the Trust's website about common problems such as measuring blood pressure and giving a blood sample. However, it also revealed that there is scope to provide information on a wider range of topics and for different audiences. The trust may wish to consider having two sets of leaflets available – one for clinicians and one for beneficiaries and other lay audiences. In addition to the two health topics already covered (giving blood and blood pressure) it might be helpful to have the following:

- A general leaflet for clinicians about Thalidomide damage, explaining that limb difference is only one aspect and that Thalidomide survivors may have 'hidden' damage
- A leaflet for physiotherapist and complementary therapists such as osteopaths and chiropractors, about the possible differences in Thalidomide survivors' joints and the implications for manipulation/treatment
- A leaflet about the importance of rehabilitation/re-ablement and advice about rehabilitation equipment suitable for beneficiaries with upper limb damage

Ideally all leaflet should be available as printable and downloadable PDFs which both beneficiaries and clinicians could access. Beneficiaries could also ask their GP practice to keep an electronic copy of relevant leaflets with their notes, so that if they see a healthcare practitioner who didn't know them (e.g. for a blood test) the information is readily available.

Another issue which was touched on briefly by a few participants, was the risk of inappropriate treatment in an emergency situation (e.g. after an accident) and how to convey basic information about Thalidomide to help reduce this risk. One approach (which is used by some people with long term conditions) would be the option to carry an emergency information card, explaining that the card holder is a Thalidomide survivor, providing some key information about Thalidomide damage and perhaps giving the Trust's website address.

Network of Specialists – As was noted in Section 3, participants very much welcomed the Trust's efforts to develop a network of specialists with knowledge and experience of treating Thalidomide survivors. There was support for this network being extended beyond orthopaedics and neurology to cover specialties such as cardiology, gastroenterology, and pain management. Participants wanted access to such specialists for both diagnosis and treatment of specific problems. However, there was also interest in being able to have a general assessment or "MOT" as one participant put it, which looked more broadly at the beneficiary's health, functioning and wellbeing, and provided advice about future treatment options and self-management. A few participants also talked about wishing they could have an MRI scan so that they could better understand how Thalidomide had affected their bodies. For beneficiaries who wanted to pay privately for an MRI, the Trust could perhaps guide them to reputable private MRI facilities and advise them about the type of MRI scans on offer and the interpretation and use of the results.

Clinical Research – Participants supported the Trust's role in commissioning clinical research to understand and find treatment options for the secondary health problems Thalidomide survivors are now experiencing. They recognised that the development of a network or specialist was in part linked to this and indeed one participant had directly benefited from participating in research, as it had led to the diagnosis of one of his health problems.

Peer to Peer Support – The value of sharing experiences and information with other Thalidomide survivors was highlighted by most of the participants. Several used the Thalidomide Facebook page to get and share information but not all participants were comfortable with social media and either just looked at the Facebook page or didn't use it at all. A few had been to the NAC annual conference and/or had been put in touch with other beneficiaries with similar health problems by the Trust. There was a strong view that there was scope for the Trust to facilitate much more peer to peer support. Several ideas were put forward:

- Building on the existing informal system of linking beneficiaries with similar problems, to create a more structured and supported '**buddying**' system. There are several model which have been tried and tested by other organisation but most involve some training for 'buddies' (especially around confidentiality, boundaries, risk etc.) and on-going support.

- Creating a **'discussion forum'** in the beneficiaries' only section of the new website. There was recognition that this would need to be moderated and managed but for some it felt like it would offer a more private space than Facebook.
- Providing **more opportunities for beneficiaries to get together**, perhaps through a regular series of smaller regional events. Participants suggested that these could combine space for beneficiaries to discuss issues informally with more formal information session, booked appointments with Trust staff and equipment demonstrations.
- Developing an **'Emotionally Fit for the Future'** session within a broader event, designed to help beneficiaries maintain or improve their mental wellbeing, through sharing experiences and learning new strategies and techniques for promoting emotional resilience.