 

**Low Mood Improvement for Thalidomide Survivors (LIfTS) Study**

**Final Report**

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##

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# Chapter 1 Introduction

For some time now the Thalidomide Trust has been aware that a significant proportion of UK thalidomide survivors are experiencing poor mental wellbeing, including low mood, depression and anxiety. Data from the Trust’s programme of Holistic Needs Assessments (HNAs) indicated a high prevalence of low mood across the beneficiary population and the Mood Survey, conducted in 2018 as phase 1 of this project provided a more detailed picture of the situation. It showed that depression (at all levels of severity) was more prevalent amongst thalidomide survivors, than the general population, with over a quarter reporting symptoms of low mood/mild depression and a slightly higher proportion reporting moderate to severe symptoms of depression. The picture was similar for anxiety, with a quarter of beneficiaries experiencing symptoms of mild anxiety and a further quarter reporting moderate to severe anxiety – a far higher proportion than in the general population. A full report from the Mood Survey was produced in summer 2019. The executive summary from the report is shown in Appendix A.

In response to the HNA findings, the Trust has been developing a number of approaches to supporting beneficiaries with mental health needs, ranging from routine regular wellbeing calls from the Health & Wellbeing team, to facilitating access to counselling and specialist treatments. The most significant development has been the introduction of ‘Talk Together’ – a structured programme of peer emotional support provided by trained beneficiary volunteers.

Whilst thalidomide survivors with depression living in the UK can also access help from their GP, many choose not to do so or have not found the treatments offered effective or acceptable (Newbronner 2017). The Trust was keen to explore ways to support beneficiaries with mild to moderate depression and anxiety. In particular, they were interested in interventions which can be (largely) delivered remotely, and in the potential for using peer support to build on their existing Talk together initiative. The Low Mood Improvement for thalidomide survivors (LIfTS) programme was designed in response to that call to action.

The Trust were aware of the work carried out by the University of York Mental Health and Addictions Research Group (MHARG) into brief psychological interventions. In particular: the CASPER study which successfully combined behavioural activation and collaborative care (i.e. supporting participants to work through an activity based programme) to address sub-clinical depression and anxiety in older people; and the CHEMIST (Community pHarmaciEs Mood Intervention Study) feasibility and pilot studies, which explored whether pharmacy support workers (given some additional training) can effectively support people with long term conditions undertaking a six session (workbook based) Behavioural Activation programme. This research has shown that a simple psychological approach called Behavioural Activation (BA), accompanied by telephone support, can reduce peoples’ symptoms of low mood.

The Trust were keen to test whether a similar six session BA programme, accompanied by peer support from specially trained beneficiaries, could help thalidomide survivors with low mood.

The element of peer support was important because many beneficiaries tell the Trust that a lack of understanding by health care professionals, of the unique and particular impact of thalidomide is a real barrier to accessing help. Overall, the study aimed to answer five questions:

* Can a six session behavioural activation intervention designed for people with long term conditions with low mood be successfully adapted for use with thalidomide survivors experiencing low mood/mild to moderate depression?
* Can volunteer peer supporters be trained to support fellow thalidomide survivors undertaking the programme and what, if any are the benefits for peer supporters themselves?
* Does peer supported behavioural activation reduce depressive and/or anxiety symptoms in thalidomide survivors with low mood/mild to moderate depression?
* Does the intervention have any wider benefits e.g. improved quality of life, reduced levels of chronic pain
* What skills, training and support are required to enable peers supporters to work safely and effectively?

This report presents the findings from the pilot LIfTS programme. It begins in this chapter with a description of the low mood programme, and an overview of: the recruitment and training of peer supporters; the recruitment and progress of participants; and the methods used in the evaluation. Chapter 2 considers the outcomes for the six beneficiaries who completed the programme, in terms of their symptoms of depression and anxiety, and general health. Unfortunately the number who completed is much lower than the original target but the results still provide a sense of the potential benefits of the programme. In Chapter 3 we discuss the experience of the Peer Supporters, including their feedback about the training and support arrangements and any benefits the programme brought for them. Chapter 4 brings together feedback about the programme from participants and Peer (and Staff) Supporters, in particular their views on the workbook and the practical arrangements for the calls, and considers the possible reasons for the recruitment problems. In the final chapter we set out our conclusions and make recommendations as to how the interventions used in the LIfTS programme could be used in future by the Trust and identify learning points for future research of this kind in the Trust.

## 1.1 Description of the Low Mood Programme

LIfTS is essentially a self-help programme with support. It is structured into six sessions, and is accompanied by a workbook. The role of the Peer Supporter is to guide the participant through the programme, helping them to get the most from it. Participants had an initial ‘start up’ telephone discussion with their Peer Supporter and then worked through each session with them, normally on a weekly basis. Typically the phone calls for each session lasted around 30 minutes.

The workbook is designed to mirror the topics covered in the sessions and is also split into six sections:

* Recognising symptoms of low mood
* The value of keeping a diary
* Three types of activity (routine, necessary and pleasurable) and planning to keep a balance
* Breaking things down to make them easier to manage
* Keeping the benefits of your activities when you have health problems
* Spotting symptoms of low mood and making an action plan to stay well

At the end of each session, the participant and their Peer Supporter would normally plan some things for the participant to do before the next session, e.g. keeping an activity diary for a week and noting their mood after doing different activities.

## 1.2 Recruiting and Training the Peer Supporters

The plan was to recruit and train six to eight Peer Supporters. An information sheet, role profile and application form were developed. The Trust then invited any beneficiaries who were interested in the role to apply. Eight people applied for the role and following an informal telephone interview with two members of the research team, they were all invited to take part in the Peer Supporter training planned for November 2018. Unfortunately three people were unable to take part in the training due to ill health or personal reasons, and so five Peer Supporters and one Staff Supporter were trained in the first session. A second training course took place in January 2019, at which four more Peer Supporters were trained (two of the three who could not attend the first session and two new volunteers).

The training for Peer Supporters took place over three days. It included sessions on: the theory behind Behavioural Activation approach; the content of each session; and how to support participants through the programme, including time to practice key skills.

After the training, all the Peer Supporters were asked to take part in an informal assessment, to check that they understood the programme and their role, and were ready to support participants. Prior to the assessment, one person decided that the role was not for them and another dropped out for personal reasons. One person did not pass the assessment, and one did pass but after one session with a participant decided that she did not want to continue. The programme therefore went forward with five Peer Supporters and one Staff Supporter.

Once a Peer Supporter began working with a participant, a member of the research team contacted them to set up regular support/supervision sessions. The sessions were an opportunity for the Peer Supporter to share any difficulties or seek advice but also enabled the research team to ensure that they were delivering the programme as intended.

## 1.3 Recruitment and Progress of Participants

All the beneficiaries who responded to the Mood Survey and were interested in taking part in the low mood programme were asked to return a Permission to Contact form giving the research team their contact details. Sixty two beneficiaries did so.

The research team then contacted them to check if they were still interested in being involved, and if they were, they were asked to complete a Consent Form. Of the 31 beneficiaries who returned their Consent Form, 22 went on to take part in a baseline interview. Nine did not have a baseline interview, either because they declined, did not respond to requests to set up the interview or had no symptoms of low mood (based on their response to the mood survey).

The baseline interviews were designed to: check that the beneficiary was suitable for the programme; gather ‘baseline’ information ahead of them starting the programme; and give the beneficiary an opportunity to learn more about what was involved in taking part. In particular their PHQ-9 depression score (see section 1.4.1) had to be between 5 and 14, indicating they had symptoms of low mood or mild to moderate depression. We also needed to check that they were not currently receiving any psychological treatment (e.g. counselling or CBT) and they did not have a significant addiction to alcohol or drugs, as this would have made them unsuitable for the programme. However, being on anti-depressants was not a barrier to taking part. Of the 22 who took part in a baseline interview, 16 were eligible for the study and 6 were not, either because their PHQ-9 (depression) score was too low (4 or below) or too high (15 or higher) or they were currently receiving another psychological treatment. Potential participants who presented with scores that were too high to take part in the study were referred back to the Trust or their GP and advised to seek help. Figure 1 below summarises these results.

**Figure 1 Recruitment and Progress of Participants**

Expressed an Interest (62)

Decided not to take part (14)

Did not respond (17)

No Baseline Interview (9)

Completed Baseline Interview (22)

Eligible (16)

Not Eligible (6)

Did not start (4)

Started but withdrew (6)

Completed (6)

Returned Consent Form (31)

Of the 16 beneficiaries who were eligible for the programme, six completed all the sessions, two completed three sessions, four took part in the introductory call but then withdrew after the first or second session, and four did not start. Their reasons for this low take-up are discussed in section 4.5.

## 1.4 Evaluation of the Programme

The evaluation of the programme had three main parts: baseline and follow-up interviews with participants; a focus group with the Peer and Staff Supporters; and short interviews/ feedback calls with participant who started but withdrew and beneficiaries who expressed an interest but did not take part. These are described in more detail below.

### 1.4.1 Baseline and follow-up interviews with participants

The baseline interviews were used to check if potential participants were eligible for the programme but they also enabled us to collect data about their symptoms of depression and anxiety, and their overall health status, prior to them taking part in the programme. Three standard questionnaires were used:

**Low Mood/Depression**

To measure self-reported depression severity we used the Patient Health Questionnaire (PHQ-9)[[1]](#footnote-1). It explores how the person has felt in the last two weeks and consists of nine questions with four possible responses to each question. For example, the first question asks:

*Over the last 2 weeks, how often have you been bothered by any of the following problems?*

*1. Little interest or pleasure in doing things*

With the four possible responses being: *Not at all; Several days; More than half the days;* and *Nearly every day.* The responses are scored from 0 to 3 giving an overall score range of 0-27. There are five scoring levels: 0 to 4 = no depression; 5 to 9 = low mood/mild depression; 10-14 = moderate depression; 15 to 19 = moderately severe depression; and 20 to 27 = severe depression. It is important to note however, that whilst this is a widely accepted measure of self-reported depression, it is not the same as clinical diagnosis of depression.

**Generalised Anxiety**

Anxiety commonly occurs with low severity depression and previous studies have shown that interventions for depression can also reduce anxiety, and so we decided to measure generalised anxiety using the General Anxiety Disorder Scale (GAD-7)[[2]](#footnote-2). The questionnaire consists of seven questions with the same four possible responses to each question as the PHQ-9. For example, the first question asks:

*Over the last 2 weeks, how often have you been bothered by any of the following problems?*

*1. Feeling nervous, anxious or on edge*

The responses are scored from 0 to 3 giving an overall score range of 0-21. There are four scoring levels: 0 to 4 = no anxiety; 5 to 9 = mild anxiety; 10 to 14 = moderate anxiety; and 15 to 21 = severe anxiety.

**Overall Health Status**

EQ-5D is a standardised measure of health status, which was developed to provide a simple, generic measure of health. It is widely used in the clinical and economic evaluation of health care and is designed for self-completion by respondents or via one to one interviews. We used the longer version of EQ-5D (EQ-5D-5L), which has the same 5 dimensions as the short version (i.e. mobility, self-care, usual activities, pain/discomfort, anxiety/depression) but each dimension has five levels: no problems, slight problems, moderate problems, severe problems, and extreme problems. Respondents are asked to indicate their health state by placing a tick in the box against the most appropriate statement in each of the 5 dimensions. We slightly altered the wording of some of the statements to ensure they were appropriate for thalidomide survivors. For example, we changed *‘I have no problems in walking about’* to *‘I have no problems in walking/getting about’*. EQ-5D-5L also includes a visual analogue scale (VAS) numbered from 0 to 100, where 100 is *‘the best health you can imagine’* and 0 is *‘the worst health you can imagine’*. This provides a quantitative measure of health as judged by the participants on the day they complete the interviews.

The follow-up interviews took place approximately four months after the participants started the programme. The same three standard questionnaires were used to reassess their symptoms of depression and anxiety, and their overall health status. These were followed by a short qualitative interview which asked about the following topics:

* What their motivation for taking part in the programme was
* How helpful they found the information about the programme and their understanding of what the programme would involve/what it was about
* What they liked or disliked about the Workbook
* How they felt about having a Peer (or Staff) Supporter and if/how this support had made a difference
* What was good or less good about the calls with their Peer (or Staff) supporter (e.g. practical arrangements, length or structure of calls)
* Whether there had been any change in their mood or general wellbeing since taking part in the low mood programme

The qualitative part of the interviews was digitally recorded and transcribed in full.

### 1.4.2 Focus Group with Peer and Staff Supporters

In October 2019, a focus group was held with all six Peer and Staff Supporters (three came to York and three joined by telephone). The discussion covered the following topics:

* Their motivation for becoming a peer supporter and understanding of what was involved in the role
* Their views on the Peer Supporter Training and how well it prepared them for the role
* Their feedback on the programme materials (e.g. the Workbook, the Peers Supporters Manual) i.e. how easy it was to use, what they found most/least useful
* The experiences of the calls with participants including practical arrangements, length or structure of calls, and how easy/difficult they found the calls
* Their feedback about the support and supervision arrangement including the level of support, whether it helped them (e.g. make use of their skills, feel more confident, or work through any difficulties)
* The benefits or challenges that being a Peer or Staff Supporter had brought for them, their participants and the Thalidomide Trust

The group discussion was digitally recorded and transcribed in the form of detailed notes and quotations, by a member of the research team.

### 1.4.3 Short interviews/feedback calls with non-completers/non-starters

Six participants started the programme but withdrew before completing. Short interviews were held with three of this group, to explore their reasons for withdrawing, and where possible gather some feedback about aspects of the programme, in particular the idea of Peer Support and the Workbook. A number of beneficiaries expressed an interest in taking part in the programme but then decided not to do so. Short feedback calls were held with four of them to understand their reasons for this.

All the participants, Peer and Staff Supporters and those beneficiaries who withdrew or declined to take part were also asked whether they thought the Trust should offer this or a similar programme as one way to support beneficiaries with low mood/mild to moderate depression. Their views about how the programme might need to change, practical arrangements and the ways in which beneficiaries could be encouraged to take part were also sought.

### 1.4.4 Analysis

The PHQ-9, GAD-7 and EQ-5D-5L results from the baseline and follow-up interviews were entered in to an Excel spreadsheet for analysis. The transcripts from the interviews and the focus group were up-loaded in to NVivo and analysed thematically. In Chapter 2 we bring together the results about symptoms of depression, anxiety, and overall health status (from the three standard questionnaires) and the interviews. We present the findings in both summary form and in six individual case studies, which together are intended to provide a sense of the possible benefits of the programme.

# Chapter 2 Outcomes for Participants

This chapter begins with a brief summary of the impact of the programme on low mood/depression, anxiety and general health for the six participants who completed it. We then present the results for each participant in six short case studies.

## 2.1 Summary of Outcomes

The overall results suggest that the programme has led to positive outcomes for participants, although with such small numbers they need to be interpreted with caution. As is discussed in the individual case studies, there are also some anomalies. For example, at follow-up one participant showed an improvement in their symptoms of depression and anxiety but rated their overall health as poorer.

### 2.1.1 Low Mood/Depression

All the participants showed an improvement in their PHQ-9 depression score, with three having no symptoms of low mood/depression at follow-up.

**Figure 2 PHQ-9 Depression Scores at Baseline and Follow-up**

###

### 2.1.2 Anxiety

All except one participant showed an improvement in their GAD-7 anxiety score, although the change was less marked, with four participants still reporting symptoms of mild to moderate anxiety at follow-up.

**Figure 3 GAD-7 Anxiety Scores at Baseline and Follow-up**



###

### 2.1.3 Overall Health Status

Overall health status was measured using EQ-5D-5. Participants were ask to rate their health (on the day of the interview) on a scale of 0 to 100 with 0 being the worst heath they could imagine and 100 being the best. Overall the average score rose from 50 to 65 but as Figure 3 below shows, two participants rated their general health as poorer at follow-up.

**Figure 4 Self-rated General Health**



The programme could have some impact on the five dimensions of health measured in EQ-5D-5 (mobility, self-care, usual activities, pain/discomfort and anxiety/depression).

However, give the programme is essentially a behavioural activation intervention, it is perhaps most likely to influence the last three. Table 1 below shows the results at baseline and follow-up for all six participants.

**Table 1 EQ-5D-5 Results at Baseline (BL) and Follow-up (FU)**

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
| Participant | Mobility | Self-care | Usual Activities | Pain/Discomfort | Anxiety/Depression |
| BL | FU | BL | FU | BL | FU | BL | FU | BL | FU |
| 25 | 1 | 1 | 1 | 1 | 1 | 1 | 3 | 2 | 2 | 1 |
| 31 | 3 | 2 | 5 | 5 | 3 | 3 | 5 | 4 | 3 | 3 |
| 37 | 2 | 2 | 4 | 3 | 3 | 3 | 3 | 4 | 4 | 3 |
| 139 | 2 | 1 | 5 | 5 | 2 | 2 | 4 | 3 | 2 | 3 |
| 153 | 2 | 2 | 2 | 2 | 2 | 1 | 2 | 2 | 2 | 1 |
| 172 | 1 | 1 | 3 | 2 | 3 | 3 | 3 | 4 | 4 | 3 |

NOTE: 1 = no problems; 2 = slight problems; 3 = moderate problems; 4 = severe problems; and 5 = extreme problems

## 2.2 Participant Case Studies

Below we present brief case studies for each of the participants who completed the programme. The participants have been given pseudonyms and some of their biographical details have been change or omitted to preserve their anonymity.

### 2.2.1 Participant A - ‘Rebecca’

Over the past year Rebecca had experienced some quite big changes in her life. She had had a bad experience whilst having an operation and was having ‘flashbacks’ which left her feeling quite anxious and low. Also she had recently got a dog which was positive but had involved significant lifestyle changes and, at least initially, had restricted her freedom to go out and do her usual activities.

**Impact on Low Mood, Anxiety and General Health**

Prior to taking part in the programme, Rebecca recorded a PHQ-9 score of 6, indicating symptoms of mild depression. At follow-up this had fallen to 2 i.e. no depressive symptoms. Her GAD-7 score was also 6 at baseline indicating symptoms of mild anxiety. This had fallen to 1 at follow-up i.e. no symptoms of anxiety.

Across the five dimensions of EQ-5D-5, Rebecca reported a very modest improvement in her level of pain/discomfort (moving from moderate to mild pain and discomfort). Similarly her results for Anxiety/Depression also showed a modest improvement (moving from slight problems to no problems with anxiety or depression. Curiously her self-rated health score actually fell from 70 to 40. There is no obvious explanation for this, other than the fact that EQ-5D-5 is a snapshot of how the person is feeling on the day, and people naturally have good and bad days.

**Wider Benefits and Challenges**

The low mood programme had really helped her adjust to having the dog and think about creating ‘me’ time:

*“Before the dog I used to go to the gym, go for a massage, meet friends and things but now it’s gone. I’m starting to go back to the massage now and back to swimming and different things. Back to what I did before the dog. It’s just trying to find ‘me time’, you know what I mean. Like I’m going out tomorrow with my friends and I’ve got a dog minder”*.

She had found the idea of putting activities into routine, necessary and pleasurable categories very helpful and was trying to get a balance into each day. Overall she felt that the programme had shown her how to deal with low mood and she felt that if she had a period of low mood again she would know *“how to get back on track”*. She also explained that she had found it very helpful being able to talk to someone outside her family and friends and she has now moved on to have regular calls with a Talk Together volunteer.

### 2.2.2 Participant B - ‘Ben’

In recent years Ben and his partner have both had health problems that at time left him feeling quite low. He also experiences chronic pain which affects his mood. He is not working but has a very busy life, so he tries to pace himself to avoid getting too tired. In the past he has tried a number of approaches to help with low mood. He felt the programme might remind him of some approaches he was already familiar with but also give him some new tools.

**Impact on Low Mood, Anxiety and General Health**

Before starting the programme, Ben’s PHQ-9 score was 11, indicating moderate depressive symptoms. At follow-up his score had dropped to 4 i.e. no depressive symptoms. His GAD-7 was very high prior to the programme (15) suggesting symptoms of severe anxiety. At follow-up his score dropped substantially to 8 i.e. symptoms of mild anxiety.

On overall health status, Ben’s self-rated health score showed a marked change going from 30 to 75. Across the five dimensions of EQ-5D-5, he reported a slight improvement in his mobility (moving from moderate problems to slight problems) and his level of pain/discomfort had also improved slightly (moving from extreme pain and discomfort to severe pain or discomfort).

**Wider Benefits and Challenges**

Thinking about the benefits he had gained from the programme, Ben emphasised that it had enhanced the ‘tools’ he had for dealing with periods of low mood: *“It definitely made a difference. It reinforced some of the things I already knew and gave me other tools and other ways to think about things and it definitely helped”*. He found listing activities and then referring back to the list and reflecting on how the activities had made him feel, particularly helpful. Overall, Ben noted that his mood had been more stable and he had felt better able to deal with ‘down times’:

*“Since the sessions have ended…really from the start to the finish…I’ve had odd off days but everyone has off days…I’ve been on a remarkably even keel. When things get [bad]…I can go back to some of the tools that I was taught about, basically just to divert attention away from things, which has been good for me because normally I’m a grumpy sod but I’m not up and down as much as I was”.*

### 2.2.3 Participant C - ‘Moira’

Moira had lost a close family member relatively recently and felt she was still dealing with the bereavement. Although she had had some bereavement counselling she felt her mood was still quite low and hoped the programme would help her. At the time she took part in the programme, she was having major work done on her house and so it was quite a stressful period.

**Impact on Low Mood, Anxiety and General Health**

Moira’s PHQ-9 score before the programme was 14, the highest of all the participants. This score indicates she had symptoms of moderate depression. The follow-up interview showed a very small fall to 13. She also had the highest GAD-7 anxiety score, a 17 (i.e. symptoms of severe anxiety) and again this only fell very slightly, to 15, after the programme. However, she emphasised that she was in an unusually stressful period: *“This is not a normal time and I hope it’s going to settle down in to a more normal life when all these problem* [with her building work] *have been sorted out*”.

Unfortunately, on overall health status, Moira’s self-rated health score fell from 35 to 25, and there was little change in the five dimensions of EQ-5D-5. She reported a slight improvement in her level of Anxiety/Depression (moving from being severely anxious or depressed to moderately anxious or depressed) but her level of pain/discomfort had worsened marginally (moving from moderate to severe).

**Wider Benefits and Challenges**

Despite recording only very marginal improvements in her depression and anxiety scores, Moira did feel she had benefitted from taking part in the programme. She explained:

*“It has made me more aware of low mood and what signs to look out for and to realise how I’m feeling and why I’m feeling like that, and that there are ways to move out of that but because the pressure is so great at the moment, I don’t think I could fight my way out of a paper bag! If things were less stressful and I was coping with normal, everyday issues, then I feel it is a good strategy to use”.*

She felt the programme had changed her thinking. In particular it helped her think about how she could structure her day better and, even in a stressful period, build in a few minutes for something enjoyable. She described one change that she has made:

*“I try to do something at least once a week, as I said about Sunday meeting up with a friend and going for breakfast. I try to do something even with the* [grown up] *children if it’s the three of us and just get out and have just a couple of hours away, going to the cinema. You know, trying to make a break in the week to do something pleasurable”.*

Over the years Moira has had relatively little contact with the Thalidomide Trust but her Peer Supporter had encouraged her to get in touch with the Trust to see if they could support her over this stressful period, which they have, and so this had been an added benefit.

### 2.2.4 Participant D - ‘Simon’

Over the years Simon has had several periods of low mood/mild depression and he is currently taking antidepressants. A close family member had passed away a few months prior to him taking part in the programme and he felt he was still coming to terms with that loss. He no longer works full time but has a busy, active life.

**Impact on Low Mood, Anxiety and General Health**

Prior to taking part in the programme, Simon recorded a PHQ-9 score of 10, indicating symptoms of moderate depression. At follow-up this had fallen to 7 i.e. mild depressive symptoms. His GAD-7 score actually increased from 5 to 8 but both these scores fall within the mild anxiety band (GAD-7 score of 5 to 9).

On overall health status, Simon’s self-rated health score rose from 60 to 75. Across the five dimensions of EQ-5D-5, he reported some improvement in his mobility (moving from slight problems to no problems) and his level of pain/discomfort (moving from severe pain and discomfort to moderate pain or discomfort). However, he reported a slightly higher level of Anxiety/Depression (moving from being slight anxious or depressed to moderately anxious or depressed).

**Wider Benefits and Challenges**

Simon said that taking part in the programme had improved his mood but he felt it was hard to measure objectively because he was still coping with bereavement. He said that doing the programme had motivated him to get back to doing regular exercise and he was particularly positive about the role of his Peer Supporter in motivating him:

*“Well I mentioned to her about seeing my personal trainer and going swimming and she would say to me, ‘well when are you going to do those things then?’. ‘Oh next week’…‘well are you sure because you sound as though you are pushing things back’. And I kind of said yes you’ve got me actually. So I did do something differently. I said I’m going to go swimming on Sunday and I’ll make an appointment with the personal trainer as soon as I’ve finished this call, which I did”.*

### 2.2.5 Participant E - ‘Jenny’

Jenny had experienced significant health problems in the previous year and had then been made redundant from her job. She was feeling quite low and so when a member of the Trust’s Health and Wellbeing team suggested that she take part in the Low Mood programme she thought she would give it a try. She liked the idea of talking to another thalidomide survivor as she felt they would more easily understand the problems she faced and how she felt.

**Impact on Low Mood, Anxiety and General Health Scores**

Before starting the programme, Jenny’s PHQ-9 score was 8, indicating mild depressive symptoms. At follow-up her score had dropped to 3 i.e. no depression. Her GAD-7 score dropped by just one point from 3 to 2 and both scores indicated that she had no symptoms of anxiety.

In terms of overall health status, Jenny started with quite a high self-rated health score of 80 but even this showed improvement, rising to 95. Across the five dimensions of EQ-5D-5, at baseline Jenny reported ‘slight problems’ in all dimensions but at follow-up she reported having no problems in relation to ‘usual activities’ and depression/anxiety.

**Wider Benefits and Challenges**

Jenny felt the programme had made a difference to her mood. She explained: *“I’ve got a more positive outlook I think. I don’t know, I think I was a bit depressed. Sometimes I’d sit and find tears running down my face for no reason but I haven’t had that for months”.* For her, having another thalidomide survivor as her Peer Supporter was important. She enjoyed the calls with her Peer Supporter and has stayed in touch with them through Talk Together. With regard to tools and techniques, she also explained that she has always broken tasks down to make them more manageable but the programme made her realise that she could do this even more. As a result of the programme she resumed some activities she’d enjoyed in the past: *“I did one or two things…I did a bit of gardening which I haven’t done for a long time”.*

### 2.2.6 Participant F- ‘Peter’

Peter has been very fit and active for most of his life but in the last few years he has experienced joint/back problems, chronic pain and lack of energy. As a consequence he had recently taken early retirement and was generally finding it difficult to do many of the activities he enjoys. He also explained that he was feeling more socially isolated because he didn’t have the energy to cope with socialising. At the time he was contacted about the programme, he was at a low point and hoped it would *“give me tools to get me out of the hole”*. He explained that over the years he had tried many different strategies to help him with low mood and depression, including counselling, mindfulness and self-help approaches. He particularly liked the idea of talking to another thalidomide survivor.

**Impact on Low Mood, Anxiety and General Health Scores**

Prior to taking part in the programme, Peter recorded a PHQ-9 score of 12, indicating symptoms of moderate depression. At follow-up this had fallen to 9 i.e. mild depressive symptoms. His GAD-7 score fell slightly from 8 to 7 but both these scores fall within the mild anxiety band (GAD-7 score of 5 to 9).

On overall health status, Peter’s self-rated health score rose substantially from 30 to 80, but there was little change in the five dimensions of EQ-5D-5. He reported a slight improvement in his level of anxiety/depression (moving from being severely anxious or depressed to moderately anxious or depressed) but his level of pain/discomfort had worsened marginally (moving from moderate to severe).

**Wider Benefits and Challenges**

Peter felt that because he had had counselling in the past and had used self-help approaches to improve his mood, he didn’t learn any new tools or techniques but it did refresh his memory. However, he did find the idea of replacing activities he could no longer do with activities that he could do (i.e. that are ‘functionally equivalent’) helpful.

*“So I think it certainly helped change my thinking…It’s not what I can’t do it’s what I can do and that was a game changer. When that part of it came up, I felt very resistant to it initially because it’s kind of saying ‘you’ve got to give up what you were doing and find something else’, and part of me was going ‘I don’t want to give it up!’ but the whole process really kind of helped me adjust my thinking – ok you can’t do that but you can do this”.*

Peter explained that over the years he has had relatively little contact with the thalidomide community and so for him having a fellow thalidomide survivor as a peer supporter had been especially valuable:

*“I think it was quite timely. I think I said that when we spoke before. I’ve been through a lot of counselling and stuff but I’ve never had a session or process where there was somebody who I know would completely understand where I was coming from. I found that was the most useful element of the whole thing. I was able to talk to [Peer Supporter]. She knew what I was talking about because she was living it herself”.*

The results presented here are based on the small number of participants who completed the programme, and do need to be interpreted with caution. However, all of the participants reported some positive outcomes, and five out of six showed a clinically significant change in their mood (as measured by their PHQ-9 score).

# Chapter 3 Peer Supporters

An important aim of the LIfTS programme was to test whether volunteer Peer Supporters could be trained to support fellow thalidomide survivors undertaking the programme, and to explore whether there are any benefits for Peer Supporters themselves. This chapter draws on the findings from the focus group with Peer Supporters. In it we discuss what motivated beneficiaries to become Peer Supporters, their experiences of working with participants, and the benefits and challenges of their involvement with the programme.

## 3.1 Becoming a Peer Supporter

All the Peer Supporters said that they had become increasingly aware of friends and peers within (and outside) the thalidomide community, who were experiencing low mood or depression and anxiety. They speculated on the reasons for this, in particular highlighting giving up work, life changes, pain, getting older, developing new health problems, and finding it harder to cope with disability. One Peer Supporter felt that it was about changing identity:

*“So many of our identities are founded upon what we can do – ‘we can do this just like anyone else can’. It is obvious that as our bodies are wearing out, an identity that’s based on ‘we can do this just like anyone else can’ is going to be quite fragile, if we reach a point where we stop being able to do it. So putting up that mask of ‘I can do just what everyone else can do’ just gets increasingly difficult to keep up when we sense that we are falling behind. And I was hearing from lots of people that they are just becoming exhausted by trying to keep that mask in place”.*

Two Peer Supporter had experienced low mood themselves in the past and felt the support they needed hadn’t be there at that time. For all these reason they were motivated to help other beneficiaries. However, some also said that they were interested in learning something new and having skills that they could use inside and outside the thalidomide community. Two Peer Supporters said that they had been raising this issue with the Trust for some time. They were pleased that the Trust had responded and so felt they should volunteer.

All except one of the volunteers who attended the training were clear about what the LIfTS programme was and broadly what their role would be. However, two volunteers who had previously trained as counsellors found it very difficult to accept that because the programme is essentially a supported self-help intervention, it was not appropriate to use their counselling skills (other than in a very broad sense e.g. listening skills). Both of them decided not to continue as Peer Supporter, although for one of them the main reason for withdrawing was a family crisis.

Overall the Peer Supporters enjoyed the training and felt it had prepared them well for their roles. However, some people would have liked more one to one time to practice working through each session, so that they felt more confident going into the first session with a participant:

*“I didn’t feel that we did enough of the actual process and therefore I had to do a bit more learning for myself before I felt I was comfortable to go straight in and do a call because you don’t go on one session – you have to know what the next session and the next one after that”.*

There were mixed views about the length of the training, with some people feeling it was too short, others too long and one that it was about right. Some Peer Supporters were unsure about the amount of theory covered, although they quite liked the challenge of learning about something new:

*“I think I got a little bit lost with some of that theory but I did some Googling afterwards and found some stuff out and compared with my notes…Whether I needed to understand all the theory I don’t know but I wanted to master the theory. I wanted to understand what all the behavioural activation stuff was based on”.*

It is probably impossible to get the length and intensity of the course right for everyone, as inevitably people are starting from different points. Perhaps the answer is to cover all the core information and skills in the course, and then offer additional phone sessions for those who feel they need more practice to build-up their confidence. All the Peer Supporters agreed that ideally there would be a relatively short gap between completing the course, passing the assessment and starting to support a participant. Unfortunately, because of recruitment problems, a few people had a gap of several weeks.

## 3.2 Working with Participants

Peer Supporters described a number of practical difficulties that arose when working with participants, particularly around arranging and making the phone calls. The initial plan was that Peer Supporters would phone their participants via the virtual call centre (set up for the Talk Together service), as this would avoid participants and Peers Supporters having each other’s telephone numbers. This created some problems when setting up the first call. If the participant was unavailable and the Peer Supporter left a message suggesting a time for the call or requesting them to ring back, the participant had to ring the Trust and ask them to pass their response on to the Peer Supporter (creating a delay and extra work for Trust staff). However, once the Peer Supporter and participant were in contact and had regular calls set up, the system largely worked well. To overcome the problems around setting up the first call, the University provided the Peer Supporters with mobile phones but this approach also had problems: the phones provided were very old (i.e. not smart phones with touch screens); some didn’t have important features such as a loudspeaker facility; Peer Supporters were understandably reluctant to use/carry two phones (or even three if they already had work and personal ones); and some Peer Supporters preferred a particular type of mobile phone because they found it easy to use.

*“For me, the setting up the first call was a bit of a nightmare but after that the virtual call centre worked fine and we never used the mobile phone because again it didn’t do what I needed it to do.”*

Most of the Peer Supporters would have been happy to use their own phones for the calls. However, this first group of Peer Supporters are perhaps a little unusual in that several of them were active in the thalidomide community and so their numbers were already known to many beneficiaries. Some specific issues arose for participants with hearing impairment. One explained that she could connect her bone anchored hearing aids to her i-phone which improved her ability to hear but she could also lip read and so she and her Peer Supporter communicated via FaceTime. Sign Live was set up for another potential participant but in the end she didn’t take part in the programme.

The other major challenge was simply getting participants to respond: *“I obviously had problems for a long time getting a beneficiary who would engage. One wouldn’t return calls or text or anything. The second one we made an arrangement and then they just weren’t around”*. It often took Peer Supporter several attempts to fix a time for the first call. Usually, after the first call there were fewer problem, as the Peer Supporter and participant would book times for the calls. However, one peer Supporter noted that reminder texts were useful:

*“I think was very helpful was to be able to do a text reminder, so ‘I’m calling you at 4.30 today’ and I did that about 3pm beforehand…just a quick text, so that when you did call at 4.30 or whatever time it was you haven’t caught them out... I felt from previous experience of contact with beneficiaries, some of them do lead quite kind of chaotic lives. So even though you might have an arrangement to speak at a particular time on a particular day, they are kind of surprised when you phone on the dot at the agreed time!”*

It could sometimes be difficult to find mutually convenient times for the calls, especially when the participant and/or the Peer Support were both working or were very busy. However, by planning ahead and being organised most people were able to deal with this.

In terms of the length of the calls, most took around 30 minutes but the first call was usually a little longer (40 to 50 minutes). Most felt that the time commitment was manageable but that some flexibility was needed:

*“So I was probably 50 minutes on the first one and about half an hour-ish or 35 minutes on the subsequent ones. But it depended on the situation the beneficiary was in, and what they had felt throughout the week and what they really felt they needed to talk about to be able to move forward. I found that trying to keep to the time constraint made the session harder because instead of dealing with the issue that the beneficiary had, you were trying to squash things into the timeframe.”*

Generally, the Peer Supporters found working with their participants interesting and enjoyable. At the start of each call they had to ask a question designed to assess whether the participant was at risk of self-harm or suicide. During the training some people had felt uncomfortable about this but in practice it didn’t present any problems. The Staff Supporter noted:

*“I tend to talk to a lot of beneficiaries when we do what we call ‘wellbeing calls’. Where I found this really interesting was the risk assessment question that you ask. I know it’s not a very nice sort of question to actually ask but when someone is in low mood its very interesting when you can actually ask that question and if there are any risks there, there are actually ways you can talk through to see just how serious that risk is with that person.”*

Whilst the Peer Supporters were supporting a participant, they were expected to have regular support/supervision calls with a member of the research team. Where possible these calls took place a day or two after the call with the participants. All the Peer Supporters found them helpful as they provided reassurance and a chance to learn or get advice: *“Getting the calls from* [research team member] *was very helpful because maybe you’d done something that you could improve on next time”.* However, there were mixed views about the frequency of the calls:

*“I certainly found the calls useful at the beginning, when I wasn’t as sure of the process but after that, to be honest it would have been better if I had had something to tell her, that I needed to talk about rather than…I felt it was a bit repetitive, if that makes sense”.*

The consensus was that if the LIfTS programme were to continue in some form, ‘lighter touch’ support/supervision arrangements could be put in place.

## 3.3 Benefits and Challenges

It was clear that all the Peer Supporters found it gratifying to see their participants use the tools in the workbook and benefit from the programme. Even where there wasn’t a marked change in the participant’s mood, there were sometimes other benefits. One Peer Supporter who has been a volunteer for the Trust for several years, had encouraged her participant to contact the Trust for support about unrelated problems and this had had a very positive outcome. Others highlighted how much some participants had gained from talking to a fellow thalidomide survivor and felt that the cross over with the Talk Together service was very valuable.

Several of the Peer Supporters felt that they learned about ideas and approaches that could transfer in to their own lives, in particular ways to prevent low mood:

*“What I got out of it was the sense that it’s a good technique for when you’re not necessarily in a low mood, when you’re healthy but if you’re aware of the vicious circle approach, you can prevent yourself ever entering the circle. I found there is potential in this being some sort of preventative tool. So it’s a bit like telling people to brush their teeth rather than wait until you’ve got problems and have to go to the dentist. It’s kind of on-going hygiene. So you could see this approach as a preventative measure to stop getting into a situation of low mood. I learnt a lot from that.”*

For the programme as a whole, perhaps the biggest challenge was the number of people who did the training but then did not pass the assessment or decided not to carry on and take up the role. After the training, the time commitment in being a Peer Supporter is not huge. However, once they start supporting a participant they do have to ensure that they are available roughly once a week for around six to eight weeks, to do the support calls. Changes in family and personal lives cannot always be predicted, but perhaps some of the volunteers had not quite appreciated that being a Peer Supporter did require a consistent, if short term, commitment. Three Peer Supporters had previously undertaken some training as counsellors. One had no problem adapting her approach to the LIfTS programme and proved to be a very good Peer Supporter. However, the other two found it difficult to accept the very structured nature of the programme, and decided not to continue. The previous research projects, on which the LIfTS programme is based, also found that those with counselling training often found it difficult to adapt their approach. These may be important issues to keep in mind, if the programme continues and there is a need to recruit more Peer Supporters.

# Chapter 4 Feedback about the Programme

Together the participants (including those who withdrew from the programme) and the Peer and Staff Supporters provided very valuable feedback about the pilot programme. Their views about the workbook and the acceptability of peer support are particularly important. Their feedback, together with comments from those who decided not to take part in the programme, also provides some insights into why take-up for the programme was low, and how this might be addressed.

## 4.1 Understanding of the Programme

Most participants said that they had a reasonable understanding of what the programme was about and what taking part would involve, before they started. They felt the information provided was clear, with enough but not too much detail. However, some said that their understanding developed as they worked with their Peer Supporters: *“It took on more meaning and understanding as we discussed it and went through it.”* Participants were encouraged to look at the workbook before the first call with their Peer Supporter. Whilst generally this was helpful, one participants highlighted the risk of people dismissing the approach as too simple and highlighted the value of the Peer Supporter bringing it to life:

*“When I said I’d do it I thought ‘I don’t know what I’ve let myself in for really’, and then I got the booklet. I think if people had to booklet and read it they might think ‘this isn’t going to be very helpful so why bother with it’, because I felt you needed somebody to talk through the booklet with you and discuss things and bring things out in your life – make it relevant to that person’s life. Because some of the questions are quite straightforward I suppose and I could imagine that some people might think I won’t bother. I wouldn’t have got nowhere near as much out of it if I hadn’t had [Peer Supporter] to talk to and that. As I say, I would have probably scan read that book and then put it one side and not done anything with it…If you’re in a low mood you’re not motivated.”*

One beneficiary who expressed an interest in the programme but then didn’t take part thought that it was only for people whose low mood was directly linked to their disability. He said - *“my disability isn’t the cause of my issues”*. The causes of low mood can be multiple and complex but regardless of the root cause many people can benefit from behavioural activation approaches. This is perhaps an important point to convey if the programme continues. A Peer Supporter noted that before taking part, participants need to understand that it is essentially a self-help programme (with support) and so they have to be willing to engage. He wasn’t sure if this would suit some beneficiaries:

*“There were a couple of individual who came to mind…and I remember thinking this really wouldn’t work for them unless they are willing to change their outlook on life. I kind of wonder whether for some them for whom it didn’t work (or didn’t take it up), they suddenly realised that they have to do something, this is a help to them, to help themselves, which just doesn’t fit in with their way of viewing the world.”*

Of course when someone is experiencing low mood, finding the motivation to do something about it can be hard. Also, people will have different perception of what ‘help’ with low mood means, and may not have considered that ‘self-help’ is an option. We return to the issue of recruitment problems and low take-up in 4.5 below.

## 4.2 The Workbook

All the participants, including those who withdrew from the programme felt that the workbook was clear and easy to use, saying things like – *“It was all very well set out, very logical and very clear”* and *“It was relatively easy to use. I didn’t have any problems with it”.* A participant who had tried various approaches to dealing with low mood in the past felt that it was quite simple and perhaps best suited to *“someone coming in fresh”*, but he had nevertheless found it a useful *“aid memoir”*. Another, who had also tried other ways to help with low mood said – *“It reinforced thoughts and sort of educated rather than dictated to you. It gave me the tools to do what I needed to do”*. One of the Peer Supporters noted that the steps in the workbook are quite small and so – *“You can find yourself very easily working ahead to the next one but I don’t think that matters because the reality is that most beneficiaries…will have a number of different areas of life they can apply it to”*. However, one participant commented on the overlap between sections and felt there was danger of too much repetition.

The workbook begins by explaining what low mood is and how to recognise the symptoms of it. Both participants and Peer Supporters felt this was very valuable. A participant explained:

“*I mean the fact that it took you through a sort of learning journey was incredibly useful because it kind of taught you to recognise low mood for what it is. And it taught you some kinds of coping strategies…it taught you some things you could do at the time, in the moment, where you could sort of say ‘Oh hello, yes this is low mood, I know what to do about this”. So you know, you would use the tools from the book and sort of improve your mood having learnt how to a) recognise it and b) sort of head it off.”*

In terms of the specific tools and techniques described in the workbook, all the participants mentioned at least one that they had found helpful. One Peer Supporter said his participant had found great value in keeping a diary and noting how different activities had made her feel. An example of the diary sheets is shown in Appendix B. He explained that the diary sheets had also given them material to work on in future sessions. Several participants said they liked the idea of putting activities into the ‘routine’, ‘necessary’ and ‘pleasurable’ categories. They found it helped them to plan their day and get a balance between the three types of activity. Another participant specifically mentioned the section on breaking down task to make them easier to manage. She had always done this to some extent but it reinforced the value of it – *“I realised that I could break them up further. If you get tired doing one thing you can come back to it later or perhaps do it some more the next day”*.

More generally, the workbook had been adapted for thalidomide survivors from a version developed for people with long term conditions. None of the participants had concerns about how appropriate it felt for thalidomide survivors but one of the Peer Supporters felt that it could have been made even more relevant to thalidomide survivors and people with physical disability in general.

## 4.3 Views about Peer and Staff Support

The Trust has for many years involved beneficiaries as volunteers but this was the first time they had been involved in a specific mental health initiative. Perhaps inevitably, using Peer Supporters brought both benefits and challenges. A participant summed up this dilemma very well:

*“It’s a good idea because we understand each other’s experiences to an extent but I think we have to be careful because we are a closed group of people…I mean on the one hand there is a certain amount of shared experience and empathy but on the other hand there’s a sort of ‘Ooh that’s a bit too close for comfort’.”*

Most of the participants, and those who withdrew, acknowledged that they had some reservations about talking to another beneficiary. Again they noted that the thalidomide community is small and people either know, or know of, many other beneficiaries. They felt it might be uncomfortable speaking to someone that they might later meet at a thalidomide event or socially. Even more importantly, whilst they knew the Peer Supporters were bound by rules of confidentiality, there was still a concern that something might be let slip to other people in the thalidomide Community.

*“I was worried about confidentiality and whether things would be kept private and not spread around the rest of the thalidomide community. That was a concern but I soon worked out that [Peer Supporter] was very professional and… that reassured me that what was said between the two of us was strictly for this low mood study and wouldn’t be for wider consumption so to speak. So I felt comfortable talking to her after the initial session.”*

One participant, who has been very active in the thalidomide community, didn’t feel comfortable having a Peer Supporter but was happy to have a Staff Supporter, and this worked well for him - “[Staff Supporter] *was top drawer. Probably the right person for me…I’d like to see more staff involvement”.* By contrast, there were two participants who specifically wanted to talk to a fellow thalidomide survivor. One said that it was the prospect of talking to another beneficiary that had convinced her to give the programme a try. She had felt really encouraged by the calls with her Peer Supporter and has stayed in touch with them through Talk Together. Another participant explained that he would have considered support from a member of staff but peer support had worked well for him because his Peer Supporter could relate to his experiences. Both participants and Peer Supporters agreed that the ideal would be to give beneficiaries the choice, not only of a Peer or Staff Supporter, but also an independent supporter, perhaps a non-beneficiary volunteer or someone from another disability organisation.

Lastly, several participants commented on how ‘professional’ their Peer Supporters were, describing them as *“well trained”* or *“a natural”*. They felt that the role was not something everyone would be able to do, and emphasised that this sense of professionalism and competence was very important for building up the trust needed for the relationship to work.

## 4.4 Telephone Support Calls

All the participants said that they were comfortable with telephone support, although as was noted in Chapter 3, for one participant with a hearing impairment, FaceTime worked better as she could both listen and lip read. There was general agreement that ideally people should be given the choice of a phone call or a video call of some kind (e.g. FaceTime, Skype, Zoom), with Sign Live available for those who prefer to use British Sign Language. A few participants report technical problems with some calls (e.g. poor line quality) and sometimes it wasn’t easy to find mutually convenient time for calls. However, mostly these were minor concerns and the feedback was generally positive:

*“It was great because we got into a routine. We stuck to the same day and the same time because he was working and I was working. It was ideal to speak to him in the evening, about 6 o’clock or half six. It was great and he’d text me if he was a bit late on the train.”*

Most participants also felt that the length of the calls was about right. One participant said – [the call] *seemed to reach its natural conclusion. It didn’t seem hurried, it didn’t seem too long and laborious or whatever. It felt for me about right”.* A couple of participants commented that they did have the sense that the Peer Supporters were trying to contain the length of the calls but they didn’t think this was necessarily a bad thing, acknowledging that there had to be some kind of constraint.

Five participants had an introductory call and then six support calls, and they all felt this was about right. The other participant had an introductory call and four support calls. However, he explained that this was because he and his Peer Supporter worked through the workbook quite quickly and he was quite happy with the number of calls. Both participants and Peer Supporters liked the idea of having a follow-up call, two or three months after completing the programme. They felt that this would motivate people to keep using the approaches they had learnt about and provide an opportunity to pick up on any problems or concerns.

## 4.5 Recruitment Problems/Low Take-up

The biggest challenge faced by the LIfTS project was the recruitment of participants. At the outset we had hoped to have at least 20 beneficiaries complete the programme. As we describe in Chapter 1, around a third of those who responded to the mood survey (n=62) expressed an interest in taking part. Of the 31 who returned a consent form, only 16 took part in a baseline interview *and* were eligible, and 10 of these either did not start or withdrew after one or two calls. What might be the reasons for this low take up? The project evaluation suggests that there were three possible reasons.

**Feeling too low Mentally and/or Physically**

One of the main reasons appeared to be people feeling too low mentally and/or physically. A few beneficiaries recognised that they had low mood or mild/moderate depression but perhaps because of this they didn’t feel they could cope with a structured programme and/or didn’t feel ready to talk to a Peer/Staff Supporter. One beneficiary explained that at the time she had the first call with her Peer Supporter she was coping with problems in her wider family and she had recently come off anti-depressants. She said:

*“I thought I’d give it a go but I’m not ready to do it yet. I know that sounds silly but I just can’t wrap my head around questions and everything at the moment… Usually I don’t have a problem sharing things but the way things are sitting in the family at the moment…I have to work that through myself.”*

Interestingly, the same beneficiary said that despite only having one support call with her Peer Supporter it had helped her a little – *“What she* [Peer Supporter] *suggested was work through…you know do simple things. I mean I wasn’t even opening the post but that’s changed”.* Other beneficiaries described how physical health problems had made it difficult for them to take up or complete the programme. This was partly about feeling physically unwell and finding it difficult to focus on something new, but often they had a lot of GP and clinic appointments and couldn’t face fitting in another regular slot, even for a few weeks. As one person explained – *“It was just one more thing. Do I need to make time for one more phone call? How much effort will I have to put in?”.* Two of the participants who completed the programme talked about having had quite serious health problems in the past year, which had made them feel low. For them the programme came along at the right point, when their physical problems were settling down. This suggests that a good time to offer beneficiaries help with low mood might be after a period of poor health, rather when they awaiting a diagnosis or undergoing tests and treatment.

**Feeling too Well**

Another reason people gave for withdrawing or not starting the programme was that at the time it was offered they felt quite well, despite their depression scores (PHQ-9) in the baseline interview suggesting that they had low mood. Often they had experienced low mood in the past and perhaps still had low days but generally felt they were ok. One of the benefits of this type of behavioural activation programme is that it can be preventative i.e. helping people to recognise symptoms of low mood and take steps to address it sooner rather than later. Perhaps this aspect of the LIfTS programme was not explained clearly enough and should be highlighted more, if it continues.

**Talking about Mental Health to a Peer**

One beneficiary said that he though the programme was a good idea but in the end decided he felt uncomfortable talking about mental health. The Peer Supporters also felt that some beneficiaries might not want to acknowledge that they were struggling with low mood, especially to another thalidomide survivor who appears not to have any problems. As we discuss in 4.3 above, only offering support from a peer may also have put some people off taking part. There was clearly a general concern about confidentiality and other people within the thalidomide community ‘knowing your business’. A participant who withdrew after three sessions said *“Me personally, I would have preferred an outsider. I think that would make us feel more comfortable because it’s such a small community…they need to be independent. Not even the Trust staff – they need to independent from the Trust”*. However, this was not her reason for withdrawing. By contrast, another person explained that she had only been a beneficiary of the Trust for about eight years and didn’t really feel part of the thalidomide community. She felt that many of the original beneficiaries have strong bonds and she didn’t have the same sense of identity, perhaps making the idea of ‘peer’ support harder to accept.

More generally there was sense that the timing of when people were offered the programme was key - catching them at a point when were ready to think about addressing their low mood and receptive to trying a supported self-help approach. Both the participants and the Peer/Staff Supporters had a number of suggestions for promoting and improving take-up of the LIfTS programme, if it continues, and these are discussed in the next chapter.

# Chapter 5 Conclusions and Recommendations

The number of beneficiaries who completed the LIfTS programme was small and so the results need to be interpreted with caution. However, all of the participants reported positive outcomes, in particular an improvement in their mood, with some also feeling less anxious and/or reporting improvements in their general health. The Peer Supporters also felt they had benefited from taking on the role. The experience of supporting participants and seeing them improve had been positive, and they had learned new skills which they could use within and outside the thalidomide community. Some said they had learnt things which they could transfer to their own lives, in particular ways to prevent low mood. The Staff Supporter also felt she had learnt valuable skills which she has been able to use in other areas of her work.

There was general agreement from participants and Peer Supporters that the LIfTS programme should continue in some form, as one of a range of approaches for supporting beneficiaries with poor mental wellbeing. There was recognition that this type of supported self-help behavioural activation programme will not suit all beneficiaries with low mood/depression. However, it is relatively simple and low cost approach, which potentially could help a number of beneficiaries each year. If the Trust does decide to continue the LIfTS programme, we would highlight the following issues/recommendations:

* Using a number of approaches to identifying beneficiaries who might benefit from the programme. Contacts (e.g. HNAs and Wellbeing Calls) which provide an opportunity to explore someone’s mood, gauge if they are receptive to addressing low mood and allow time to briefly explain the programme are ideal. However, other activities such as Talk Together, Volunteer support contact and Proof of Existence calls might also be good times to mention that the programme is available and see if a beneficiary is interested in learning more about it.
* Catching people at the right time (i.e. when they are experiencing low mood *and* are receptive to the idea of addressing it) appears to be crucial in getting people to take up and engage with the programme. For this reason the Trust might want to particularly identify beneficiaries who have recently experienced: physical health problems; a decline in function, especially if this has led to them need additional support (e.g. personal assistance/personal care); a change in their working lives such as retirement/ redundancy; a bereavement or other life event such as relationship breakdown; or who have new responsibilities such as caring for family member
* Explaining and promoting the programme is likely to be crucial for improving take-up. Suggestion made by participants and Peer Supporters included:
* Providing information about the programme on the Trust website, and possibly even making the LIfTS workbook available for people to view
* Using personal stories (probably anonymised) to illustrate how the programme has helped other beneficiaries. These could be written or perhaps take the form of an audio interview
* Getting a participant and/or Peer Supporter to talk about the programme at the NAC Annual Conference and/or the Trust’s local meetings
* Consider undertaking some further work with the current group of Peer Supporters and participants to see if: any additional amendments to the workbook are needed; and whether an electronic or large print version should be produced for beneficiaries with visual impairment
* Offering beneficiaries the choice of a peer, staff or independent supporter. Some work would be needed to identify where independent supports might come from but suggestions included non-beneficiary volunteers and/or a reciprocal arrangement with another charity
* Training more peer/staff/independent supporters if necessary. The Trust could consider ‘training a trainer’ so that in the future the programme can be largely run ‘in-house’. This may be both more cost effective and more convenient
* Make it possible to conduct the support call sessions by telephone (e.g. via the virtual call centre or on a mobile phone provided by the Trust), FaceTime/Skype or Sign Live
* The Trust will need to establish a supervision/support system for supporters, ideally from someone trained in psychological therapies. It could be ‘lighter touch’ that the system put in place of the pilot project but it would need to ensure that:
* Peer, Staff and Independent Supporters all have access to support and advice throughout the time they are supporting a beneficiary doing the programme
* There is a system in place for identifying participants who are at risk of self-harm or suicide and a protocol for deal with any risks identified (both during and outside ‘working hours’) as part of the Trust’s Safeguarding Policy.
* Introducing a follow-up call perhaps 2 or 3 months after the beneficiary has completed the programme, to see how they are getting on, and the option to call a staff supporter at any point if they need encouragement/advice about using the tools in the workbook or even wished to repeat some sessions from the programme

The evaluation of the LIfTS programme suggests that thalidomide survivors with low mood/mild depression can benefit from a self-help behavioural activation programme, accompanied by peer or staff support. However, catching people when they recognise that they are experiencing low mood, and feel ready to get help with it, is key. It is recommended that the relatively simple and low cost approach offered by LIfTS should continue to be provided by the Trust, as part of a range of options for supporting beneficiaries with poor mental wellbeing.

# Appendix A - Mood Survey Report Executive Summary

**1. Introduction**

Poor mental wellbeing, including low mood, depression and anxiety, is a growing concern within the thalidomide community. Thalidomide survivors experiencing these common mental health problems can and do seek help from their GPs and may be referred on to other psychological therapy services. However, many choose not to seek help or have not found the treatments offered effective or acceptable. The Trust was therefore interested in exploring alternative ways to support thalidomide survivors with low mood or mild to moderate depression and anxiety, and in particular, the scope for using peer support. They commissioned the Mental Health and Addictions Research Group (MHARG) at the University of York to undertake a pilot study, to test a six-session Behavioural Activation programme, accompanied by peer support from specially trained beneficiaries. The study is called LIfTS or Low Mood Improvement for Thalidomide Survivors.

The first stage of the LIfTS study was a Mood Survey of all beneficiaries. The overall aim of the survey was to gather data that would provide a more detailed picture of the extent and severity of depression and anxiety amongst UK thalidomide survivors. The survey questionnaire had five sections:

* Biographical Information - three questions about gender, home circumstances, and work situation
* Depression – thePatient Health Questionnaire (PHQ-9) was used to measure self-reported depression severity. PHQ-9 explores how the person has felt in the last two weeks and consists of nine questions with four possible responses to each question. The overall score range is 0-27, and the results are presented against five ‘levels’ of depression severity: 0 to 4 = no depression; 5 to 9 = mild depression; 10-14 = moderate depression; 15 to 19 = moderately severe depression; and 20 to 27 = severe depression
* Generalised anxiety - the General Anxiety Disorder Scale (GAD-7 was used to measure generalised anxiety levels. GAD-7 also explores how the person has felt in the last two weeks and consists of seven questions with four possible responses to each question. The overall score range is 0-21 and the results are presented against four ‘levels’ of anxiety severity: 0 to 4 = no anxiety; 5 to 9 = mild anxiety; 10 to 14 = moderate anxiety; and 15 to 21 = severe anxiety
* Overall health status – we used the EQ-5D-5L to measure of health status on the day the person completes the questionnaire. EQ-5D-5L has five dimensions: mobility; self-care; usual activities; pain/discomfort; anxiety/depression, and a visual analogue scale (VAS) numbered from 0 to 100, where 100 is *‘the best health you can imagine’* and 0 is *‘the worst health you can imagine’*.
* Open questions - At the end of the survey we asked three open questions: what activities or pastimes do you enjoy; what things in your life help you to feel positive; and is there anything else you would like to tell us about your mental wellbeing?

The survey was sent to beneficiaries by the Trust at the beginning of September 2018. Responses were returned directly to the research team in Freepost envelopes. The survey closed in mid-October. In total we received 182 completed survey forms, giving a response rate of 40%. The data from the survey, including the responses to the open questions, was entered into and Excel spreadsheet. Each response was given an identification number. We then transferred the anonymized data to SPSS for analysis.

**2. Profile of Survey Respondents**

Of the 182 survey respondents, 92 (53.5%) were women, 80 (46.5%) were men and 10 did not give their gender. In terms of living circumstance, around two-thirds lived with their partner/spouse or their partner/spouse and other family members, and almost a quarter lived alone. For work situation: just over a third (61/34.1%) said they were unable to work because of their disability or health problems; a further 22.3% (n=40) had chosen not to work in order to preserve my health/functioning: 22 (12.3%) were working full time; and 18 (10%) were working part-time.

**3. Depression and Anxiety**

The results of the survey showed that for depression, 43.4% (n=75) of respondents had no depression. Just over a quarter (27.2%/n=47) had mild depression (i.e. low mood). Almost a third had moderate to very severe depression: 23 respondents (13.3%) had moderate depression; 16 (9.2%) had severe depression; and 12 (6.9%) very severe depression. On average, male respondents had higher PHQ-9 scores (more depressive symptoms) than female respondents but this difference was not statistically significant. The prevalence of all levels of self-reported depression appeared to be much higher amongst the thalidomide survivors than the general UK population, but similar to other groups with early acquired/early on-set disabling conditions.

For anxiety three quarters of respondents had no anxiety (n=91/51.7%) or mild anxiety (n=41/23.3%). The remaining quarter had moderate to severe anxiety: 26 respondents (14.8%) had moderate anxiety and 18 (10.2%) had severe anxiety. These proportions are much higher than the general population. On average, male respondents had higher GAD-7 scores (more anxiety symptoms) than female respondents but this difference was not statistically significant. In addition, being unable to work was associated with higher depression (PHQ-9) and anxiety (GAD-7) scores. There was no association between living alone and higher depression and anxiety scores.

**4. Overall Health Status**

The mean score for beneficiaries’ self-rated health was 63 (out of a 100) which compares to 81.7 for the UK population aged 55-64. The range of responses was huge, although half fell within the score range of 45 to 80. The responses to the questions about mobility, self-care, usual activities, pain/discomfort, and anxiety/depression were spilt into two groups – No Problems/Problems. For all the dimensions, there were more respondents in the ‘Problems’ group than in the ‘No Problems’ group but the difference was most striking for Pain/Discomfort and Usual Activities.

**5. Conclusions**

The Mood Survey has provided a much more detailed picture of depression, anxiety and health status amongst UK thalidomide survivors than was previously available. There are three key findings. The PHQ-9 results suggest that all levels of depression are far more prevalent amongst thalidomide survivors than the general population. The GAD-7 results suggest the picture is similar for generalised anxiety. The results from these two questionnaires, together with the responses to the open questions, suggest that there is a group of beneficiaries, perhaps 10% to 15%, with very poor mental wellbeing. The open questions confirmed some of what was already known about the effect that declining health, pain, and loss of function is having of beneficiaries’ mental wellbeing. However, they also revealed the wide range of experiences, attitudes and circumstances within the thalidomide community. This reinforces the need for an approach to tackling poor mental wellbeing that is both flexible and targeted, and could include addressing physical problems such as disabling chronic pain, which increase the risk of low mood and depression.

# Appendix B - Workbook Diary Sheet

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
|  | MondayDate: | Tuesday Date: | Wednesday Date: | ThursdayDate: |
| AM | e.g. washing up after breakfast – mood score 5 |  |  |  |
| PM |  |  |  |  |
| Eve |  |  |  |  |
|  | FridayDate: | SaturdayDate: | SundayDate: | Instructions: |
| AM |  |  |  | Rate yourmood:Please enter anumber from0 to 10 to rateyour mood foreach activitythat you do0 (low mood) to10 (goodmood/happy) |
| PM |  |  |  |
| Eve |  | e.g. watching TV – mood score 7 |  |

1. Kroenke, K., Spitzer, R., Williams, J. (2001). PHQ9: Validity of a brief depression measure. *Journal of General Internal Medicine*, 16(9):606-13. [↑](#footnote-ref-1)
2. Spitzer, R., Kroenke, K., Williams, J., Lowe, B. (2006). A brief measure for assessing generalized anxiety disorder: the GAD-7. *Archives of Internal Med*icine, 166:1092-7. [↑](#footnote-ref-2)