

Transforming Care after Treatment (TCAT)

Supporting People with Individual Budgets in Lanarkshire



TRANSFORMING
YOUR
CANCER CARE
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Health & Social Care
North Lanarkshire

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The statistics in this report are the results of a self-evaluation carried out by local project staff with support from Edinburgh Napier University TCAT Evaluation Team. The views expressed in this report do not necessarily represent those of Edinburgh Napier University or Macmillan Cancer Support.

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Introduction

This is the final report from the Supporting People with Individual Budgets Project that was carried out between 2015-2017. It is one of 25 projects across Scotland (seven of which are led by local authorities) looking to transform how people are supported following active treatment for cancer. This was a joint project led by two local authority social work sections within North Lanarkshire and South Lanarkshire Councils.

The project was part of the Transforming Care after Treatment Programme (TCAT) in Scotland, a five year programme (2013-2018), funded by Macmillan Cancer Support in partnership with the Scottish Government, NHS Scotland, Third Sector organisations and Local Authorities. It focuses on supporting people affected by cancer and recognises that, to respond to the increase in the numbers of people diagnosed with cancer and the advances in treatment which has resulted in more people living with and beyond cancer it is necessary to develop new ways of providing support and aftercare.

Background

In 2015, a joint application was made by North Lanarkshire Council and South Lanarkshire Council to the TCAT Programme Board and was accepted. The plan proposed a project across both local authority areas to support adults who had been affected by cancer, through the use of a planning process and small individual budget. The application proposal sought to meet TCAT's aims of working together with people affected by cancer and of informing the discussion on the re-design of services.

Context

This section explores the context for taking forward this project, it aims to outline briefly what factors were driving this approach and essentially why the project came about:

Cancer Prevalence Rates in Lanarkshire

In Lanarkshire in 2015 there were 3742 people diagnosed with cancer and though variable year-on-year, rates have gradually increased over the last 25 years; people are living longer and there have been improvements in diagnosing cancer (Scottish Cancer Registry, Information Services Division, 2017). The most common types of cancer in Lanarkshire are lung/bronchus and trachea (with 646 people diagnosed in 2015), breast cancer (with 570 people diagnosed in 2015) and colorectal (with 426 people diagnosed in 2015), (Information Services Division, 2017).

Whilst cancer rates in Lanarkshire are predicted to increase, the population of people with cancer in Lanarkshire will of course be those newly diagnosed and those living with

cancer - and beyond. It is with this population in mind that the project proposal came about and is firmly rooted in improving practice and how people living with cancer are supported in Lanarkshire.

Policy Background

In 2016, the Scottish Strategy, *Beating Cancer: Ambition and Action* was launched setting out plans for the next 5-10 years to address a range of actions. In amongst these areas is the recognition that more needs to be done to support people affected by cancer:

“We have been rightly focused on early detection, access to high quality treatment and supporting individuals through their treatment. But as we learn from the experiences of those living with and beyond cancer it is no longer acceptable to focus on these areas alone. We now recognise that more needs to be done to improve the quality of life for people who have been diagnosed with and treated for cancer”.

(Scottish Government, 2016a:45)

The work taken forward through NHS Lanarkshire’s Cancer Strategy (2013-2016) is now very firmly embedded in ‘Achieving Excellence’ the Healthcare Strategy for Lanarkshire. A key focus is how people in Lanarkshire affected by cancer are supported to live with, and beyond, their diagnosis. ‘Achieving Excellence’ clearly sets out the aim of having an integrated health and social care system (a joined up approach) with a focus on prevention, anticipation and supported self-management (NHS Lanarkshire, 2017). It is the self-management aspect that underpins this project.

The Self Management Strategy for Long Term Conditions (“Gaun Yersel”) in Scotland defines self-management as, “the successful outcome of the person and all appropriate individuals and services working together to support him or her to deal with the very implications of living the rest of their life with one or more long-term condition”, (Long Term Conditions Alliance Scotland, 2008:5).

North Lanarkshire was at the forefront of the development of Self Directed Support and was a demonstration project in 2008. The Scottish Government introduced a ten year strategy in 2010 to take forward self-directed support (SDS) across Scotland (The Scottish Government, 2010), followed by a new law to embed this approach. This aims to increase individual choice and direction in the delivery of health and social care support. In some areas taking forward this change has been slow (Audit Scotland, 2017). The principles underpinning SDS (see Project Aims) form the backdrop to the project. The SDS approach links to the work of the Talking Points Framework (Cook and Miller, 2012), widely used across local authorities in assessing the needs of people who require social care. Talking Points is used to evaluate the support people receive which aims to

bring about positive changes in their lives, commonly known as ‘outcomes’. An outcome is typically something that cannot be seen easily:

Table 1: Outcomes Important to People Using Services

Quality of Life	Process	Change
Feeling safe	Listened to	Improved confidence/morale
Having things to do	Having a say	Improved Skills
Seeing people	Treated with respect	Improved mobility
Staying as well as you can	Responded to	Reduced symptoms
Living where you want/as you want	Reliability	
Dealing with stigma/discrimination		

(Cook and Miller, 2012)

Previously, the approach to assessments within social care was to assess against ‘outputs’, simply by addressing, ‘what can we offer you?’ This approach has changed to include assessing outcomes alongside assessed, eligible needs in social work practice (eg: ‘what would make a positive difference to you?’). It is this approach underpinning the project. See Table 2 for an example of this in relation to cancer. This relates to the case example given in Appendix 3 in relation to ‘Ann’.

Table 2:

Input	Process	Output	Outcome
Project Facilitator’s time/project design	Planning sessions	Purchasing a tablet to SKYPE	Impact on Ann (eg: feeling less lonely, feeling closer to family, connecting to the outside world)

The project is also set against the Macmillan Values Based Standard. This comprises of eight behaviours designed to bring about positive changes in practice, such as: ‘I am the expert on me’ and ‘I’m more than my condition’, (Macmillan Cancer Support, 2013).

It is good practice to offer people affected by cancer a Holistic Needs Assessment (taking into account all needs, not just those aligned to the diagnosis and treatment of cancer) either during or after treatment but we are aware that the number of Holistic Needs Assessments (HNAs) completed in Scotland were fairly low prior to the implementation of the TCAT Programme. This is another reason that the project proposal came about. Just 22% of respondents who completed The Scottish Cancer Patient Experience Survey stated that they had a care plan/HNA (The Scottish Government, 2016b:73), though it must be noted there are limitations with the data (people may have forgotten, may have not understood what a care plan/HNA was and so on).

The impact of a cancer diagnosis and how this affects people emotionally is well documented and a framework has been agreed in the West of Scotland to support those affected by cancer and those who have very specific psychological support needs. The health and wellbeing model in the framework addresses a range of post-diagnostic support and the work of this project is aligned to the areas of 'living with cancer and resilience'. The framework outlines that gaining control will take time but improving resilience (strength) will help and that developing resilience begins with simple actions or thoughts that are practiced such as planning for the future (immediate or long-term) and learning to accept change (NHS West of Scotland Cancer Network, 2017:5).

Lanarkshire's Supporting People with Individual Budgets Project

The Supporting People with Individual Budgets Project aimed to support people, both on an emotional and practical level to live well after treatment by encouraging participants to look at areas of their lives where positive differences could be made and where this could be supported by a small individual budget of £250. For the majority of participants this was done by working in small groups, though some people chose to work on an individual basis. The focus of the work was on 'moving forward' to bring about positive changes or outcomes in their lives.

Initially it was our intention to use a Holistic Needs Assessment (HNA) as the basis for the process; but as the focus was on working with people to think creatively about their life and the use of a small budget, we were keen to sound this out with people who had an experience of living with cancer.

We met with both the national TCAT Cancer Experience Panel and our local reference group to discuss the proposal and share examples of potential paperwork that could be used to deliver the project.

The groups were very interested in the idea of the extended planning process and felt that to facilitate this in the most effective way the use of a HNA was not appropriate. Both groups believed it did not lend itself to people being encouraged to think in an expansive way about their future and preferred examples of person centre planning tools. As a result of this we developed a planning tool which encouraged people to think with more freedom (Appendix 3)

The people who took part in the project attended three sessions (Appendix 4) either at The Haven or at Maggie's Lanarkshire, with a project facilitator to:

- Hear about the project, its background and aims (Appendix 2) and to sign the 'project agreement'.
- To discuss how their sense of wellbeing could be improved and how a small budget could be used to facilitate this. Participants were supported to complete a planning template to evidence this (see Appendix 3) and examples of 'outcomes' were given.
- To share their ideas and thoughts in the group/with the facilitator who would then agree the planning template and arrange the issuing of a cheque through the council finance section.

Participants were asked to keep a receipt of how the money was spent. They were invited back to an evaluation session to illustrate this and discuss the difference it had made to them. This also provided an opportunity to give feedback in relation to taking part in the project. (All of the evaluation tools used are shown in Appendix 5).

The project was managed by a project lead, with the support of three project facilitators. These were not dedicated project posts but carried out by employees working within the two local authorities with limited time dedicated to the project within their existing workloads.

On average, participants were involved with the project over the course of six months. Between 3-4 months was given to spend the budget awarded and to then attend the evaluation session. The planning sessions were approximately 90 minutes long, in most cases running for three consecutive weeks. This was dependent on the availability of the Project Facilitators, the participants and of The Haven and Maggie's being able to accommodate the sessions.

Who Took Part in the Project?

The project supported 43 adults living in Lanarkshire (34 were female and 9 were male) and on occasions participants were accompanied by an unpaid carer (often a partner). Table 3 shows the age ranges of the participants. Around one in three was under 60.

Table 3:

Age	Number	Percentage
30-39 years	1	2%
40-49 years	10	23%
50-59 years	16	37%
60-69 years	12	28%
70-79 years	2	5%
80 and over	2	5%

Cancer is more widespread in areas where there are higher levels of economic and social deprivation. The Scottish Index of Multiple Deprivation (SIMD) lists these areas. In North Lanarkshire 22% of the population live in what are deemed the 15% most deprived areas of Scotland and in South Lanarkshire this is 13.8 %. It is clear that the majority of participants were from areas of higher deprivation as shown in Table 4. SMID data was available for 40 participants.

Table 4:

SIMD	Number	Percentage
1 highest level of deprivation	10	25%
2	10	25%
3	11	28%
4	4	10%
5	5	13%

The project's participants had a range of cancer types (see Table 5). Data was available for 42 people.

Table 5:

Cancer	Number	Percentage
Breast	23	55%
Bowel	4	10%
Lung	3	7%
Prostate	3	7%
Throat	3	7%
Cervical	2	5%
Head and neck	2	5%
Haematological	1	2%
Skin	1	2%

Ethnicity data was collected and all participants classified themselves as White, Scottish, Irish or other. A presentation was made to a small group of Polish unpaid carers and to a larger group of Urdu and Punjabi speaking carers supported by Lanarkshire Carers Centre to raise awareness of the project to others. However, no referrals into the project were made as a result. As with all North and South Lanarkshire Council services the details in relation to the project were translated into the carers' respective languages.

In terms of the living situation, one in four participants lived by themselves. The majority of participants were of working age and over 40% were in employment. Tables 6 and 7 show the living situation and economic activity of all those who took part.

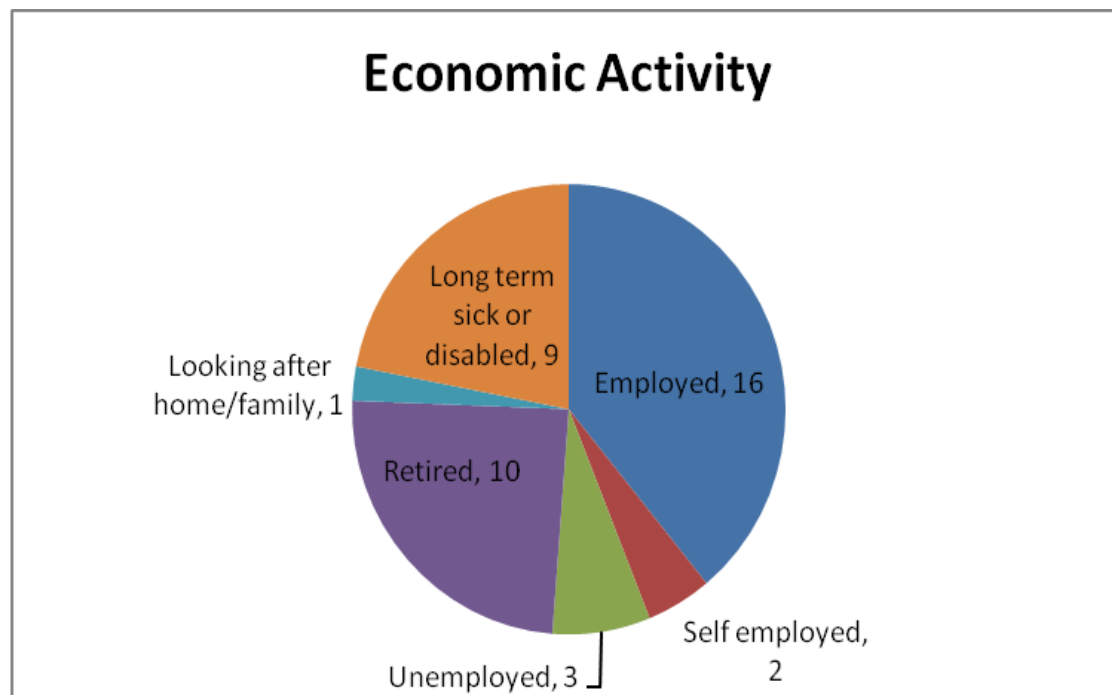
Table 6:

Living situation	Number	Percentage
Living alone	11	26%
Living with spouse/partner	28	65%
Living with children/relatives	3	7%
Living with friends	1	2%

Table 7:

Economic activity	Number	Percentage
Employed	16	39%
Self employed	2	5%
Unemployed	3	7%
Retired	10	24%
Looking after home/family	1	2%
Long term sick or disabled	9	22%

Diagram 1:



The average length of time from their diagnosis of cancer to becoming involved in the project was 12 months:

Table 8:

Length of time	Number	Percentage
Under 6 months	3	10%
Under 1 years	11	37%
Under 2 years	11	37%
Over 2 years	5	17%

How were People Referred to the Project?

The project was not widely advertised as it was always the intention to keep the numbers small and manageable. The Project Team contacted a range of partner agencies to let them know about the project and to encourage referrals of potential participants into the project, via that agency. This was to ensure that participants understood the aims of the project, its duration, the groupwork nature of it and so on.

The project was publicised through:

- The Haven (from Wishaw and Blantyre)
- Maggie's
- Lanarkshire Carers Centre (in addition through the Polish Carers' Group and the International Women's Group)
- South Lanarkshire Carers Network
- North Lanarkshire Carers Together
- Cancer Care Reviews Project (TCAT)
- Seniors Together (South Lanarkshire)
- Move More Project (North Lanarkshire)
- Nurse Consultant Cancer Care, NHS Lanarkshire

How was the Project Managed?

As the numbers of people involved were small, referrals were taken by two of the Project Team. They contacted people who expressed an interest by 'phone once a referral by a partner agency had been made. Information was then sent in the post to the participant (see Appendix 2) who was then contacted a few days later to confirm if they wished to take part and 'planning session' dates were then arranged.

The Role of the Reference Group

An overarching principle of TCAT is to increase the involvement of people who are affected by cancer in service-design and delivery. From the outset, the Project Team set out to ask people with an experience of cancer including those who had cared for someone with cancer, their views as to how the project should be implemented.

In October 2015 the project lead attended the national TCAT reference group to discuss the project and seek their advice on the project as a whole, the method of delivery including the number and length of sessions and the type of planning tools that should be used.

A focus group was held at The Haven in Blantyre in November 2015 to gain people's thoughts. The group members were also asked about the type of approach to take and the type of format to use to support the planning process. A local Reference Group was then formed to help shape the project further. This comprised of six people all of whom had either been affected by cancer or whom had provided unpaid care to someone with cancer. The group met eight times during the duration of the project, supported by the Project Team. Appendix 1 illustrates how user and carer involvement helped to shape this project.

Partnership Working

This project was underpinned by the *principles* of 'self-directed support' most noticeably, 'co-production', which simply means working together. The ethos of the project was to value and recognise those taking part as being experts in their own lives and in this sense, the power in the worker/client relationship was more evenly balanced than might be traditionally received in health or social care settings. This approach requires staff 'letting go' of some of the power they hold, "Professionals are expected to work in a more open system with multiple 'frames' for discussion and action and multiple views of situations and goals. This calls for specific skills of facilitation, trust-building, reflecting." (Hunter and Ritchie, 2007:18). The project facilitators encouraged thinking about 'what matters *to me?*', rather than 'what is the matter *with me?*' This is based upon the 'exchange model' of assessment used within social work where a good assessment is based on exchanging the thoughts, views and ideas of both the client and the worker.

This was a partnership approach in that two local authorities were working together on the project, along with NHS Lanarkshire and partner agencies: The Haven and Maggie's Lanarkshire who kindly hosted the planning sessions and the evaluation sessions. Referrals were also made to the project from both agencies but also *to* both agencies from project participants. Partnership working was also evident through cross-referring, to and from the carers' organisations for extra support, to income maximisation schemes and to other health professionals.

The support from the staff and volunteers at The Haven and at Maggie's was very much appreciated and valued by the Project Team. Staff from both agencies were also available should any of the participants needed additional emotional support as a result of their discussions during the planning sessions.

Very few referrals were made from health professionals though in part this may be because people accessing support from health professionals may have still been undergoing intensive treatment and so may not have met the project criteria.

Within Lanarkshire, there were two other TCAT projects underway as the Supporting People with Individual Budgets Project was developing and so the three projects 'combined' to form a Lanarkshire wide steering group to aid greater partnership working. This effective way of working meant that key participants from NHS Lanarkshire, WoSCAN, local authorities and the third sector could attend a single meeting and share the learning across all of the Lanarkshire based projects.

Project Aims

The main aim of the project was: 'to work co-productively with people affected by cancer at the conclusion of their treatment to establish what would assist their survivorship and support this with a small individual budget of £250' (as referenced in the final project proposal).

Further project aims were:

1. That people have increased confidence in their lives through directing their own support after treatment
2. That in recognising people as experts in their own care, self-esteem increases
3. That informal/unpaid carers are supported through this approach as equal partners in care planning
4. That the five legal principles of self-directed support (outlined below) underpin this approach in supporting people to achieve good outcomes:
 - Involve people to say what they think they need support with in their day-to-day lives
 - Make sure people are given information to make informed choices
 - Work with individuals (in collaboration) in agreeing how to support them
 - For people to have their right to dignity respected
 - For people to have the right to participate in community life

Evaluation Methods

The project evaluation was a mixed methods approach, which means that quantitative (numerical data) and qualitative (narrative data) was captured. This was done through using a wellbeing survey (Appendix 5) at the first planning session and at the evaluation session (to measure any changes in emotional wellbeing), through a project evaluation

survey (Appendix 5) and offering participants the opportunity to be interviewed either individually or in small groups.

The evaluation session was a two hour meeting, where participants had the opportunity to speak to the project facilitator/group in relation to how they had spent their money and to evidence this. They were then offered the opportunity to speak to the Researcher from Edinburgh Napier University (ENU) supporting the project, again either individually or in small groups. The interviews involving 27 participants were taped and transcribed. Project staff were not present during the interviews conducted by ENU.

The data was analysed by ENU and through the transcriptions, common themes emerged, which are detailed in the 'Results from the Evaluation' section.

The project evaluation questions were set around the project aims and the wellbeing survey was an adapted version of the Short Warwick Edinburgh Mental Well-Being Scale (SWEMWBS) as this was felt the most appropriate survey to capture thoughts and feelings.

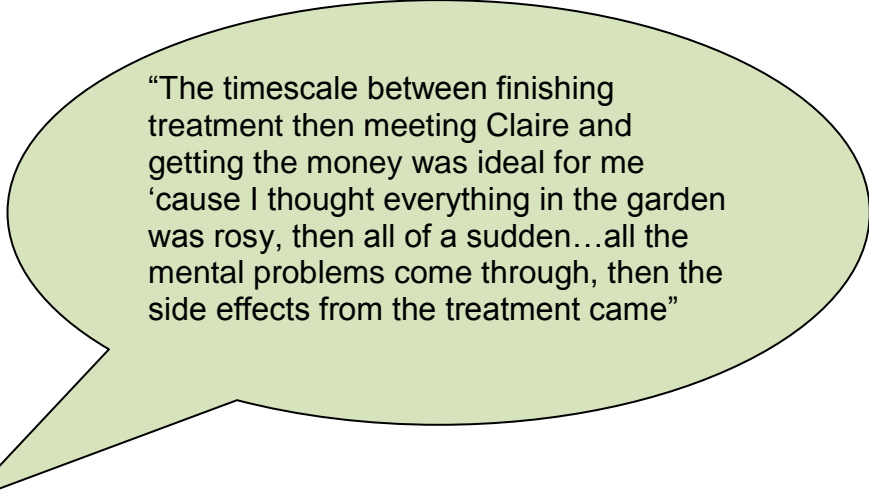
Results from the Evaluation

This section looks at the results from the project evaluation and includes the common themes that came out of the interviews/focus groups when people were speaking to the ENU Researcher. It will also focus on the survey results from the wellbeing scale (completed at the evaluation). The response rate was very high with 84% of surveys returned and 27 people interviewed out of a possible 43 (12 from South Lanarkshire and 15 from North Lanarkshire).

Themes

Timing of Service

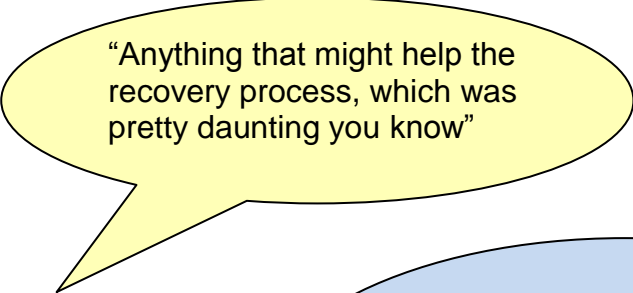
One of the elements the Project Team was interested in was the timing of the project and 94% of people felt that the project came along at the right time. There were quite a few comments of people 'hitting a low' between a few months after treatment and a year later.



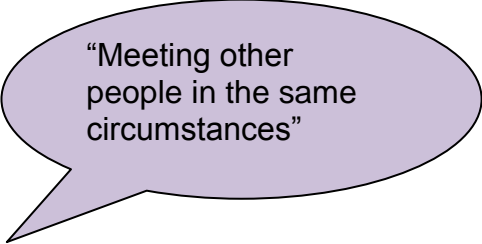
"The timescale between finishing treatment then meeting Claire and getting the money was ideal for me 'cause I thought everything in the garden was rosy, then all of a sudden...all the mental problems come through, then the side effects from the treatment came"

A lot of people mentioned the amount of medical appointments that dominate their lives during treatment and the impact of the side effects (arguably, they would have not attended this project at the same time). The focus of the project was on moving forward, *after* the main part of treatment had come to an end. However, some participants spoke of having wanted to have been offered some additional money during treatment (eg: to buy in some support with the housework, particularly parents with younger children, of covering transport expenses and so on).

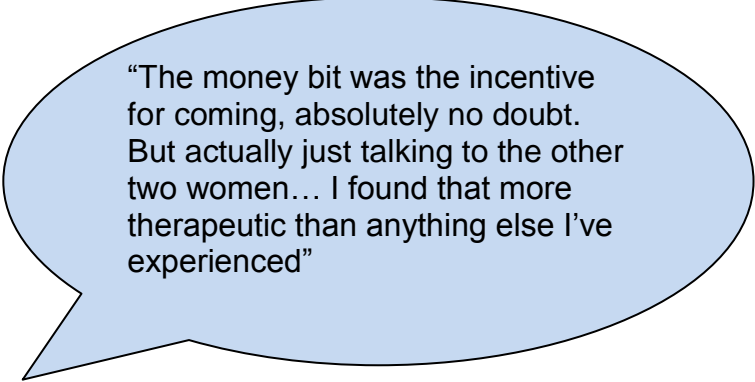
Motivation to be Involved



“Anything that might help the recovery process, which was pretty daunting you know”



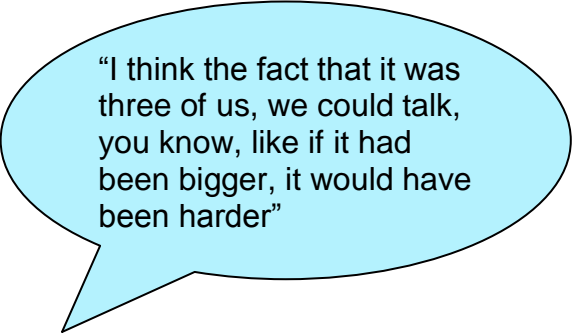
“Meeting other people in the same circumstances”



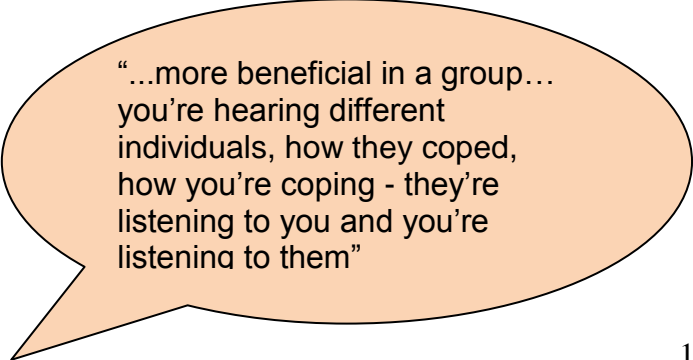
“The money bit was the incentive for coming, absolutely no doubt. But actually just talking to the other two women... I found that more therapeutic than anything else I've experienced”

There were a range of reasons why people got involved from the money being the ‘hook’, to *needing* to do something to move forward, to having the opportunity to get involved with others who had been through cancer. From the feedback received, it appears that psychologically, this project was of benefit to the participants; it aided ‘moving forward’ after treatment and appears to have given people an emotional ‘lift’ or a ‘step up’.

Groupwork



“I think the fact that it was three of us, we could talk, you know, like if it had been bigger, it would have been harder”



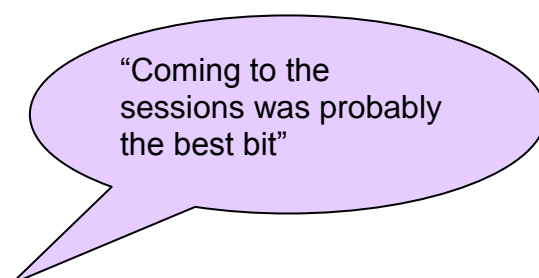
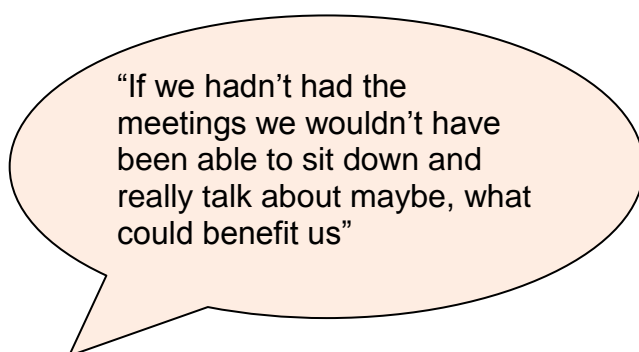
“...more beneficial in a group... you're hearing different individuals, how they coped, how you're coping - they're listening to you and you're listening to them”

The findings in relation to working in small groups were very positive, largely as people could share and learn from each other, with participants stating that the small groups worked well. This allowed for relationships to be formed and created a 'safe space' for sharing.

Sessions were often emotional but were 'supported' discussions, allowing people space and time to talk, but with a gentle focus on moving forward. Participants reported that hearing others' experiences helped them. Groups were also mixed in terms of types of cancer, age and sex, which appeared to work well; though it was noted that sometimes more vocal people can dominate a group. Some participants also worked on a one-to-one basis with a facilitator for varying reasons, which did not appear to detract from the overall experience of the project.

From this relatively small sample it is difficult to say whether this type of work best lends itself to groupwork or individual sessions though overall participants valued working in small groups. It is apparent though that it is possible to effectively deliver this work in either way as suits the participants.

Value of the Planning Sessions



When asked in the evaluation survey what people most valued about the project, no-one said the budget; 'sharing experiences' (linked to not feeling alone/being alone) was most highly rated and then 'providing motivation' and 'meeting new people'. It appears that some people had initially taken part because of the money but the money almost seemed to lose some of its significance along the way.

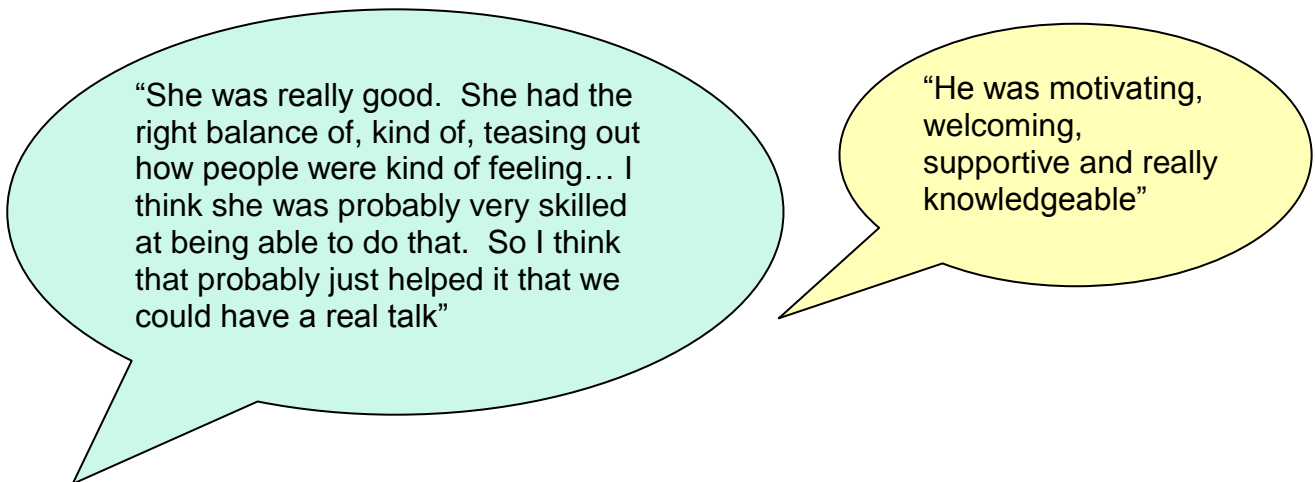
One observation was that it was evident from participants' comments that small groups were valued and that the groups were not what one participant called sad or despondent "greetin' meetings". The value was in the *approach* taken (see Appendix 3). Some participants also made new friends as a result of being together in small groups.

Several participants stated they would like additional information during the process, as to services available for people affected by cancer and as stated, some new referrals were made. Participants were asked, 'Only as a result of getting involved with the project what services/support have you accessed?'

49% of participants had accessed Maggie's
31% of participants had accessed The Haven
17% of participants had accessed a welfare rights service
6% of participants had accessed a carers' agency

Some participants felt the planning sessions could have been longer and perhaps six meetings rather than three would have been helpful, others felt there were just the right length and number of sessions.

Skilled Facilitators



One of the strengths of the project appears to be in the skills of the facilitators. It was a small enough project to be managed and facilitated well, with learning very much being a two-way process between the facilitators and the participants. The supported discussions were at the heart of this; offering participants the opportunity to talk, think and reflect in a safe, non-clinical environment. What can be inferred from the project evaluation is that the discussions played a crucial part in supporting people to take greater control of their own lives after treatment.

Participants spoke of the perspective shift after being diagnosed with cancer and of the changes this imposed on their lives. Some people spoke of the project allowing them to take control back, so that their holistic needs could be recognised and where possible met. They spoke of the 'new normal'; of adapting, however hard this was, and moving on...positively. Some participants' spoke of not having had the opportunity to talk before and this perhaps identifies a gap in support.

Whilst the facilitators were not qualified counsellors they used a 'counselling skills approach' which included the qualities of:

- Empathy – 'walking in someone else's shoes'
- Congruence – being genuine

- Showing ‘unconditional positive regard’ – for participants to ‘open up’ without fear of being criticised or judged

Moving Forward – the Approach

“It was positive, we were thinking positive whenever we came out... as far as I’m concerned my cancer has passed... so I leave it there and I just look forward and that’s what I did. It gave me something to look forward to”

“It’s about the potential; about what’s to come, how to take opportunities and not dwell on the past”

The focus of the project in terms of moving forward was a major factor in the value of the project for the participants. As evidenced in the above comments, there was also a sense from those people living actively *with* cancer of their emotional strength and of their courage in psychologically addressing their diagnosis as, a ‘long-term condition’.

Project as an Incentive to ‘Living Well after Cancer’

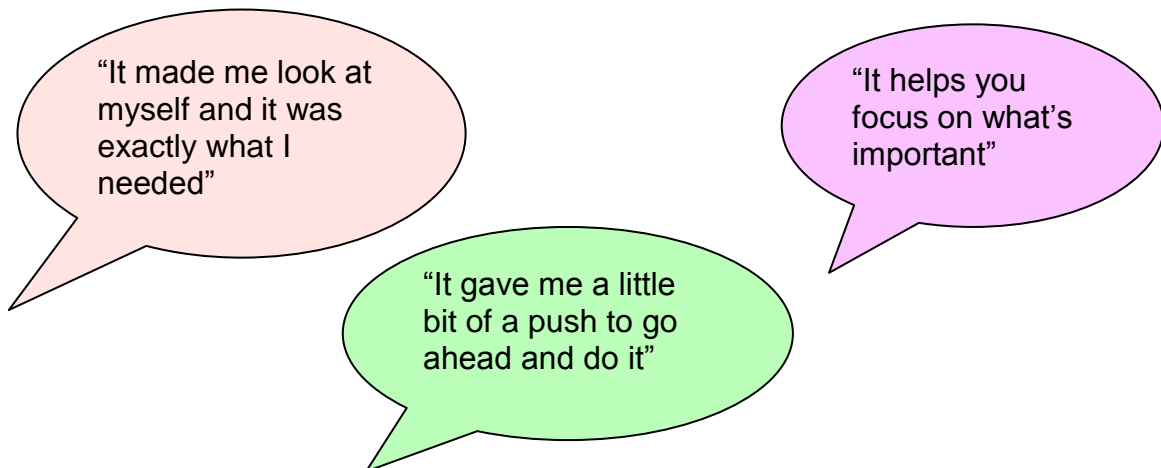
“The fact that I had to get up and dressed and out, to come was good for me”

“It’s the catalyst I wanted to start to be able to move things forward...I felt cut off... isolated... finish work and lock the door and I knew I didn’t want that to be my life”

“To be honest the money is meaningless. Like, the money... that was the incentive but to be honest if I didn’t have the money or I had to give it back, that wouldn’t be an issue. I would still have come to this”

“Would you have joined the gym without the money?”
 “No, probably not. No. I’d have thought about it and then still kept thinking about it. It helps you focus on what’s important”

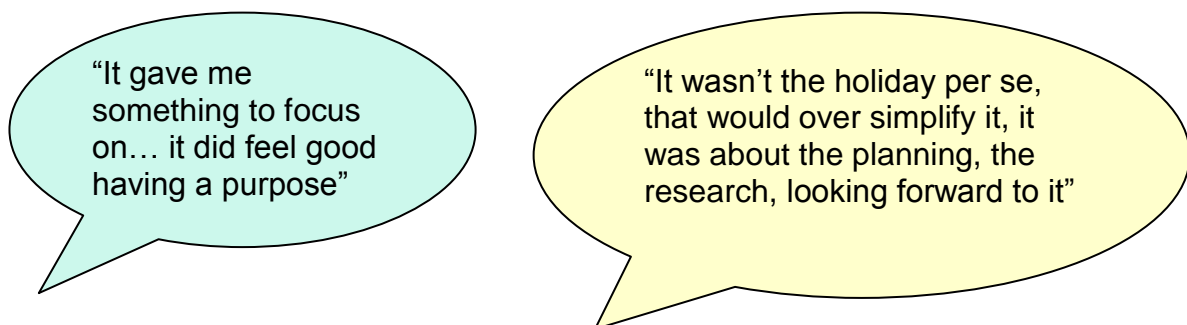
For many participants, this project acted as a 'kick start' to 'recovery'. It provided a tangible, practical framework to approach this. This can particularly be evidenced by those who used their budgets to move on into a different career, to re-train/take a course, to get involved in voluntary work, to join a gym or to have the confidence to travel. Plans were actually built upon or put into action after 'chatting' and 'reflecting'. Whilst the money helped some people to put their plans into action, as stated, it was the taking part that spurred people on.



What this says is that for some people, they were 'stuck' after having had cancer and this project acted as a lever. Whilst difficult to quantify, the approach of the project has clearly helped the majority of people move forward positively. This can also be evidenced through the wellbeing scale results in the end of this section.

Planning and Having a Purpose

Project participants had come together at first to chat about where they were at and how they wanted to move forward. They were asked to talk about what they wished to spend their budget on and why; to evidence this. These discussions offered a therapeutic framework so that participants could leave the sessions feeling 'good'; they were making plans with a clear purpose in mind.



There was a sense from some that this was just the start... that the project had offered short-term intervention with a much longer term aim:

"We prepared for it (an outing) and we were both so excited... So after that we just decided that we were going to start doing things rather than talk about it, so we have, we have done a lot of things"

"...having a goal (in what to spend the money on) was good because it makes you look forward rather than inward"

"It has made a difference... I started a new hobby... it keeps my mind off things, makes me focus on things and think about the future"

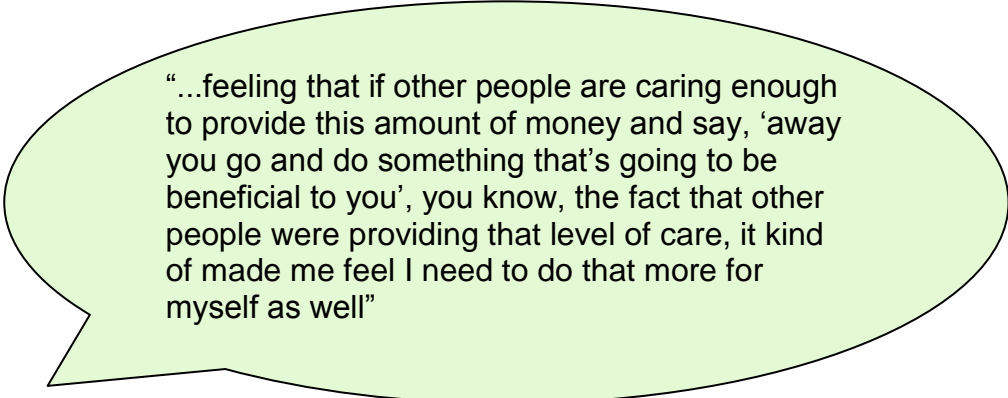
"It showed us how to move on, you know. Instead of sitting being depressed and scared of what tomorrow is going to bring, you know, we just get on with it."

Feeling Valued ("I matter")

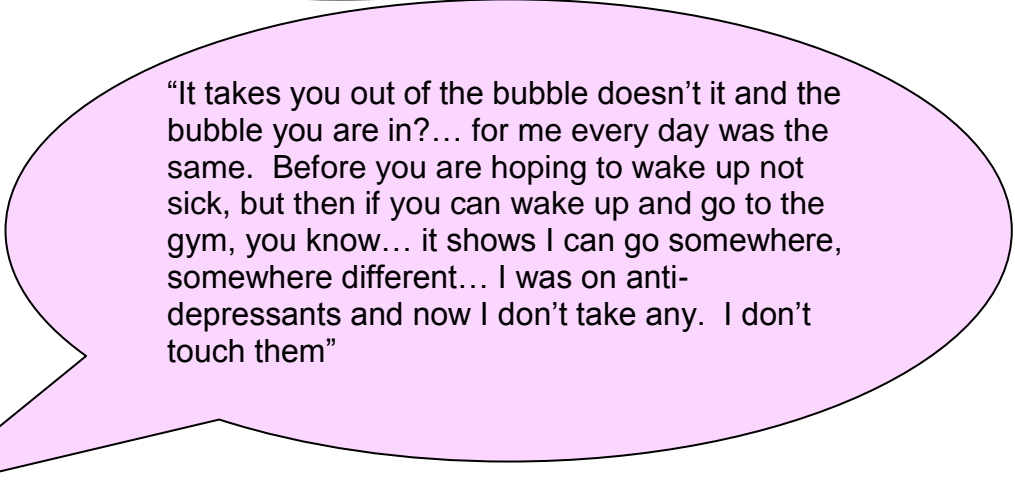
The 'softer outcomes' that participants reported on in the evaluation suggest that these can greatly influence emotional wellbeing in terms of longer-term self management. It would appear that being part of the project was highly valued because there was a shared understanding between all participants of what it was like to be told of their diagnosis but as stated, there was also a coming together to gain an emotional 'lift'. For some, this is just what they needed, for others this was the start of moving on, for others it was about living with cancer, but for the vast majority, feeling valued was at the core of this.

"You need to hear people telling you 'you are important' and eventually you say 'yes', you are right. And this [project] gives you the confidence to start thinking about yourself"

"To me the value was in having someone outside the family who would listen to me and not try and gloss over my concerns"



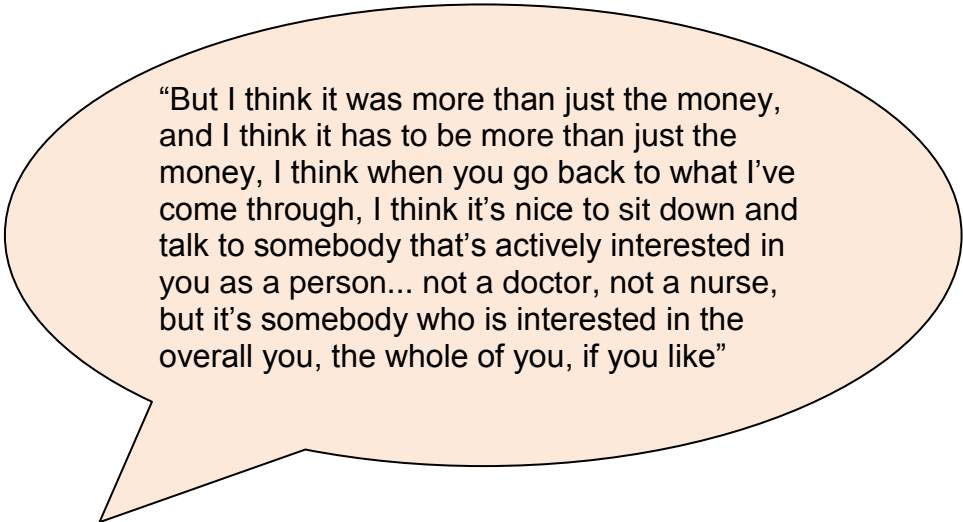
“...feeling that if other people are caring enough to provide this amount of money and say, ‘away you go and do something that’s going to be beneficial to you’, you know, the fact that other people were providing that level of care, it kind of made me feel I need to do that more for myself as well”



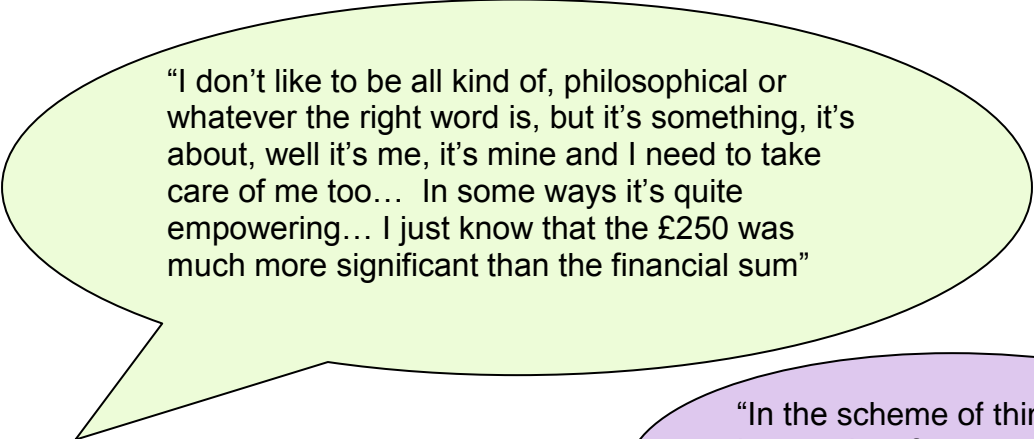
“It takes you out of the bubble doesn’t it and the bubble you are in?... for me every day was the same. Before you are hoping to wake up not sick, but then if you can wake up and go to the gym, you know... it shows I can go somewhere, somewhere different... I was on anti-depressants and now I don’t take any. I don’t touch them”

Was it about the Money?

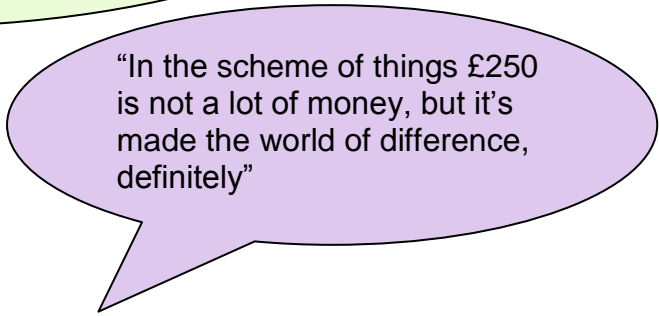
Participants reported feeling valued but this was experienced not *because* of the money but *despite* it. This was borne out by the fact that the money was a relatively small sum and for 91% of participants it was ‘just the right amount’. People spoke about the freedom of being able to spend a budget on themselves to enhance their wellbeing, of enjoying the fact that this was not means-tested and that it was not ‘prescriptive’ (eg: to be spent on white goods *only*, on transport *only*). The fact that people had the freedom to spend the money as they chose (as long as they were able to explain their reasons for doing so to the project facilitators) very much put them ‘in the driving seat’.



“But I think it was more than just the money, and I think it has to be more than just the money, I think when you go back to what I’ve come through, I think it’s nice to sit down and talk to somebody that’s actively interested in you as a person... not a doctor, not a nurse, but it’s somebody who is interested in the overall you, the whole of you, if you like”



“I don’t like to be all kind of, philosophical or whatever the right word is, but it’s something, it’s about, well it’s me, it’s mine and I need to take care of me too... In some ways it’s quite empowering... I just know that the £250 was much more significant than the financial sum”



“In the scheme of things £250 is not a lot of money, but it’s made the world of difference, definitely”

Many participants wanted to spend their budgets by doing something with a family member/carer. Some people spoke of wanting to say ‘thank you’ for the support received when they were under-going treatment; this may have been to a husband, wife, son or daughter. Some participants chose to go away on a break with that family member and spoke about ‘feeling closer’ as a result. The project’s focus has been the person affected by cancer but it illustrated the important role of carers.

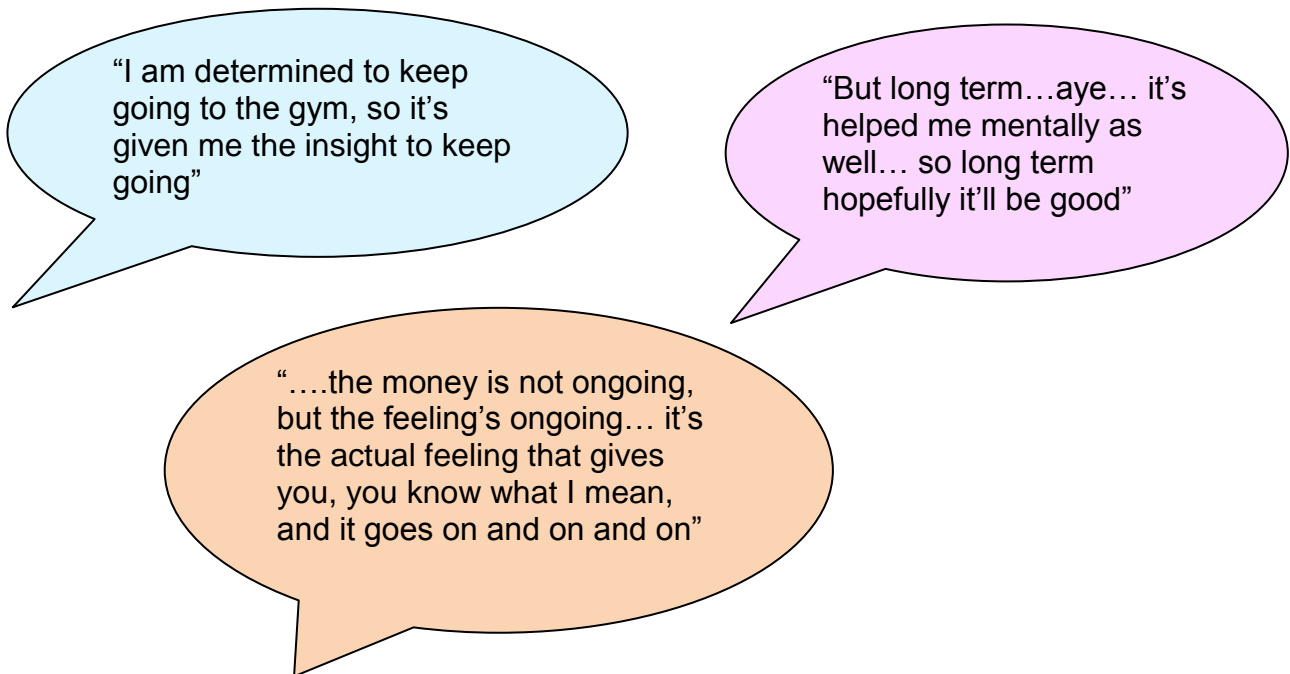
What did people spend their budgets on?

Family portrait
Raised beds/plants and flowers for the garden
Trip to London (mother and daughter)
New glasses
'Makeover'
Dinner for family and friends
Guitar lessons
Laptop
Dental treatment/"a smile"
Trip to Scarborough (husband and wife)
Fitness equipment
Hiking gear
Walking boots, dinner with Mum, a massage
Holiday to Iona, Mull and Oban (with husband)*
A dog/new earrings
Alexander Technique course/relaxation therapy
Towards a new business venture
Spa day
New watch
Towards the cost of a conference
Bra with prosthesis/weekend break
Camera
Towards a new business
Physiotherapy sessions/swimming lessons
Beauty therapy sessions/facials/electrolysis
Garden furniture and plants
Gym membership and driving lessons
Short break (husband and wife)
Towards a trip to Spain (husband and wife)
Towards a trip to Canada to visit family

* With thanks to Lanarkshire Carers Centre for additional funding from the Creative Breaks Fund for unpaid carers.

Longer Term Benefits

The longer term benefits will always be difficult to record but for some participants, this project was hugely significant in their lives and for others it will have been less so, though what is clear from the vast majority is that this project was of benefit to them.



The Technical Part (Wellbeing Survey)

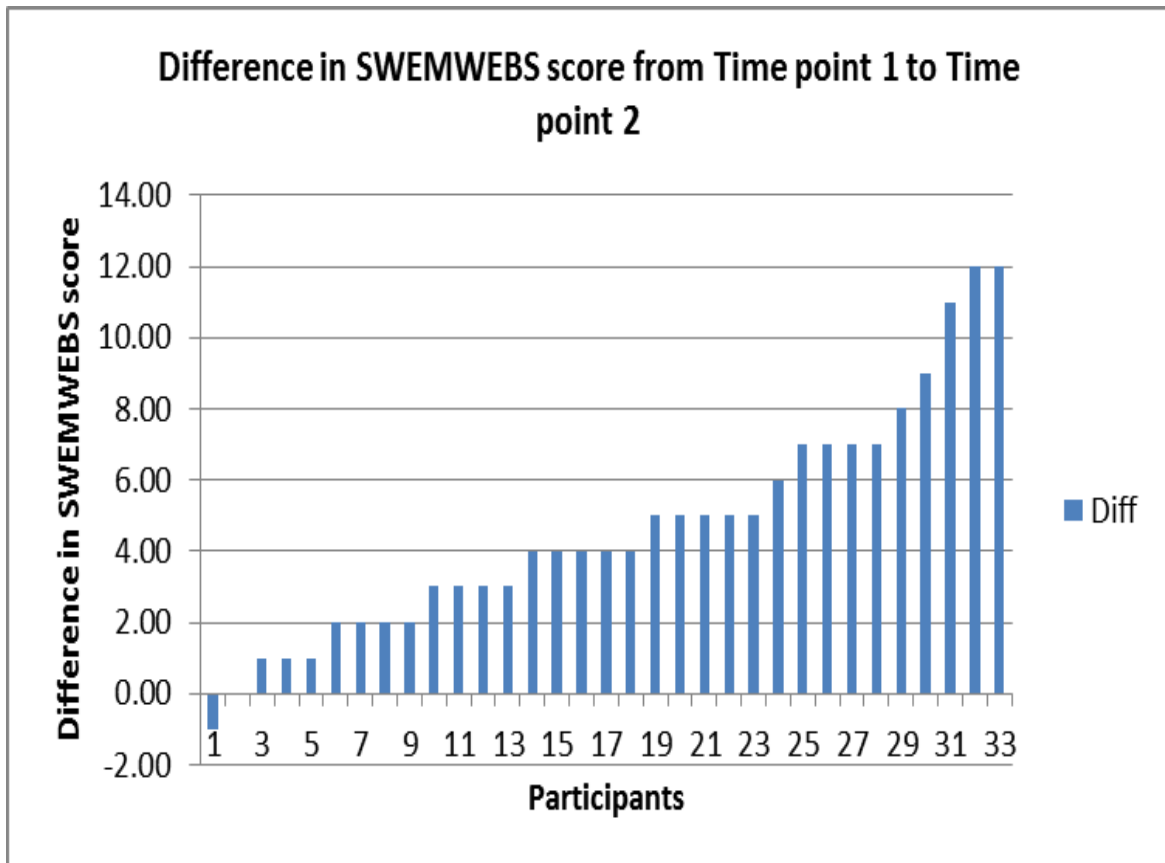
The Project Team asked participants to complete seven questions at their first meeting and again at the evaluation to record their thoughts and feelings. A shortened version of the Warwick-Edinburgh Mental Well-Being Scale (SWEMWEBS) was used (see Appendix 5).

The following information has been provided by Edinburgh Napier University in analysing the data:

The original WEMWEBS was developed for the monitoring of mental wellbeing of the general population and to aid evaluation of interventions aimed at improving this (Tennant et al, 2007). Scoring ranges for the WEMWEBS is between 14 and 70, with a higher score correlating with a higher level of mental wellbeing (Stewart-Brown et al, 2009). The SWEMWEBS uses 7 points from the WEMWEBS, therefore scoring ranges from 7 to 35. As no validated method exists for the transformation of WEMWEBS or SWEMWEBS to QALY values, the planned analysis was not possible to complete.

Data across 2 time points was available for 33 patients. Time point 1 corresponds to pre-intervention, Time point 2 to after intervention. SWEMWEBS scores at Time point 1

ranged from 14 to 31, with a mean of 22.24 and median of 22.00. SWEMWEBS score at Time point 2 ranged from 18 to 35, with a mean of 26.88 and a median of 27.00. All but one patient (n = 32) reported an increased SWEMWEBS score between time points 1 and 2. The overall difference in means was 4.64. An overview of the differences between each individual score is included in the bar graph below:



The graph shows: Difference in SWEMWEBS scores between 2 time points.

This indicates that the intervention improved the mental wellbeing of all but one participant.

Interpretation of these scores can be aided through comparison with population norms available as part of the 2011 Health Survey for England (Department of Health, 2011). In this sample (n = 7196), the population reported a mean SWEMWEBS score of 23.61 (rounded to two decimal places). This would indicate that the sample for this project had a below average level of mental wellbeing when compared to the general population prior to the intervention, which then rose to above the average following the intervention. The scores therefore suggest that the intervention had a positive impact on the mental wellbeing on the sample for which data was available.

Conclusions and Implications

The data suggests that the project may have contributed to an increase in self-reported mental wellbeing in the project sample (n = 33). The impact of potential confounders to this finding (e.g. the passage of time since completion of treatment) has not been explored in this analysis. Future evaluations should incorporate a control group to explore the magnitude of effect of confounders, and the use of a tool such as the EQ-5D is recommended to facilitate the calculation of QALYs.

The chart below shows the responses participants gave to these questions in the survey for the project evaluation.

My confidence levels have increased as a result of this project



1	2	3	4	5	6	7	8	9	10
1	1	0	0	0	3	9	11	7	3

The project has helped me with the management of my health



1	2	3	4	5	6	7	8	9	10
1	1	0	1	2	2	7	10	7	4

I feel my own expertise has been recognised as part of the project



1	2	3	4	5	6	7	8	9	10
1	0	0	1	1	1	5	7	9	10

I have felt more in control of my wellbeing since getting involved in the project



1	2	3	4	5	6	7	8	9	10
1	1	0	0	0	3	2	12	10	6

Limitations of the Project

Overall, the project has evaluated very well based on the feedback from the participants involved. As stated above there are factors, which may aid this; there is always a bias in terms of the sample (the people involved). Those taking part were in the 'right place', emotionally to do so and this may have aided the positive result. This was a small project and whilst it evaluated well further work would be required to confirm its efficacy.

Discussion

The data suggests all but one of the project participants reported improved mental health *as a result of* being involved with the project. Whilst the majority of people (over 50% in each category) reported high levels of improvement in their sense of well-being, other people found the impact more moderate, for some people this was because they felt that their pre-existing sense of confidence, self management and being in control was relatively good, for others this was because of additional health issues including the diagnosis of a further cancer. More research would be necessary to examine in greater detail how the process can be further refined to increase these levels for more participants.

In the focus groups and interviews carried out by Edinburgh Napier University, clear themes emerged, which have been explored and this discussion will now focus on the three core components of this project: the approach, the Facilitators' skills and the budget.

Undoubtedly, the approach of the project seemed to work well. It was genuinely steered with the help of the Reference Group and changes were made to the project as a direct result. The ethos of the project was always, "I am the expert on me". Though the project had a very clear framework, participants were genuinely supported to be in control; they were valued for their 'lived experience' and it appears that simply taking the time to chat, think and reflect had brought about a significant shift in perspective for some. What did appear to happen was that participants gained something almost 'invisible' from the project; they spoke highly of the approach taken (just the right amount of information, having the time to talk, of meeting others and of the skills of the facilitators). What is interesting is that some people said they had not had this opportunity to chat before, with a view to moving forward, to thinking about the future and of the 'new normal'. They valued the meetings as they were not about dwelling on the diagnosis (though people spoke about this). This kind of groupwork/intervention was 'motivational' and this was a unique approach.

Regarding the skills of the facilitators, all three are employees working within Lanarkshire; experienced in supporting people at difficult times in their lives. Their 'counselling skills approach' was valued by the participants and again appears to have been a key component to the approach. Discussions were 'supported'; these sessions

were at times practical, humorous and emotional. The sessions were therapeutic, allowing people to share what they wished to within a safe environment; peer-to-peer support was also evident with participants giving support to each other. The fact that people felt able to participate so fully is a reflection on the participants feeling *comfortable* to do so. Meeting in non-clinical environments undoubtedly aided this. Participants spoke of 'not being a number' and of 'having time to talk', though as stated, managing group dynamics is an issue if one person dominates. What worked well is that role reversal; the facilitators were not the experts here!

Lastly, the budget: Based on the premise of, "It's only the wearer of the shoe who knows where it hurts", the budget was offered initially as part of the project, to demonstrate that by giving people choice and control (financially) that they can achieve better outcomes for themselves. However, what appears to have happened is that the majority of people have reported that the process not the *budget* has given them greater choice and control in moving forward. This is an interesting finding. Could the project succeed without the money? Possibly. Participants have identified a gap in, for want of a better word, 'motivational' support. However, allowing people to *choose* how to spend a sum of money to achieve better outcomes for themselves after the main part of treatment has ended (or indeed at a time of their choosing during treatment) shows that as the 'experts', they can spend it well, ultimately to aid self-management. The project demonstrates the cultural shift that 'self-directed support' was always supposed to.

Conclusion

The findings from this evaluation demonstrate that the TCAT Lanarkshire Individual Budgets Project has been highly valued by those taking part.

The project participants highlighted the uniqueness of the approach in terms of 'motivational' support as a result of offering those taking part time to chat, think and reflect in a safe, non-clinical environment. Though the project was steered by professionals, the participants were valued as 'experts'. The project was enhanced through partnership working which shared knowledge across NHS Lanarkshire, both health and social care partnerships and a number of third sector organisations. It also identified an alternative approach to groupwork/intervention for people affected by cancer after the main part of their treatment has ended. The project has demonstrated that being able to use a small grant creatively can make a big difference to a person's quality of life and that of family members/carers. However, it appears that whilst the budget was part of the reason why people engaged with the project they found significant benefit from the process itself, with many people stating that the financial element became far less important than the opportunity to talk about their experience and discuss the future with their peers' and/or a facilitator

This evaluation has concluded that people affected by cancer want to be valued for their own expertise in terms of where they are at, emotionally and what could make a positive difference to them.

Working in this way necessitates a cultural shift in practice across health, social care and Third Sector organisations. There is a range of learning to take from this approach for those who seek to transform the care of people after treatment.

- the use of discussion and planning as a method of supporting people post-treatment to move forward in their life.
- The role of individual budgets to support this activity
- The importance of recognising people as the expert in their own life and how we promote this to support self-management and enhance service redesign.

The two year project has proved highly successful, and consideration should be given to how the learning can be applied in further ways.

Recommendations

- To look at how the reach of the project can be adapted to continue to work with people affected by cancer in Lanarkshire using this approach
- To consider the value of developing a training programme for staff so that the learning from this approach can influence practice
- To look at how this approach could be utilised by other organisations
- To spread the learning of the project beyond Lanarkshire
- For grant awarding bodies to consider the findings from this approach in terms of offering more flexibility to spend a grant 'creatively' in supporting good outcomes
- Consideration is given to how a "facing the future" perspective can be used to support people at the end of treatment

Kathie Coonagh TCAT Project Lead/Senior Officer Health and Social Care North Lanarkshire

Claire Pearson TCAT Project Facilitator/Planning Officer South Lanarkshire Health and Social Care Partnership

November 2017

Appendices

Appendix 1

Reference Group
Transforming Care after Treatment (TCAT)
Individual Budgets Project
(North Lanarkshire Council and
South Lanarkshire Council)

“You said, we did”

Our project has a Reference Group of six people (people affected by cancer and those who provide care) that helps to steer the work. The group is supported and facilitated by colleagues from North Lanarkshire Health and Social Care Partnership and South Lanarkshire Health and Social Care. The group met four times in 2016 and four times in 2017.

The following demonstrates, ‘you said, we did’ in relation to the involvement of people affected by cancer and/or carers attending the Reference Group for the project.

A focus group was also held in November 2015 as a precursor to the quarterly Reference Group Meetings and feedback from this group is also included.

Focus Group Feedback

- Asked to give examples of achieving good outcomes in the paperwork for the project. We drafted up four scenarios
- Asked to hold the sessions at more informal venues. We approached Maggie’s and The Haven (Blantyre) to use their comfortable rooms
- Asked to keep the groups small to ensure people feel comfortable. We decided on a maximum of six people attending a planning session

Reference Group Feedback

- Asked to demonstrate how risk has been addressed. We spoke about the Risk Analysis completed for the project and gave the group copies of the Project Agreement, which has been drafted to mitigate risk
- The group reminded the Project Facilitators of the use of jargon. We sent on a glossary to group members and stated we will be careful with the use of jargon/abbreviations at the sessions
- Asked the group for their comments in relation to the paperwork drafted, the group suggested the planning template is called ‘Feeling Good Plan’. We changed it to this

- Group asked if travel expenses will be covered for participants; this was agreed
- Two group members reported attending an event aimed at people who have been affected by cancer and that they had found the event to have been pitched 'too high' in terms of the approach. This was reported back to the TCAT User Involvement Manager who will be mindful of this approach at future events
- It was asked if a Reference Group member could also participate in the project. This was agreed if the person meets the criteria for the project
- Group agreed between them that Council employees affected by cancer can apply to take part as long as they meet the criteria for the project
- Asked to complete a template showing how someone might complete this for their own planning. This was done
- Group asked for clarification in relation to people who are deemed to be terminally ill whose main part of the cancer treatment has ended. This was discussed as a group and it was agreed that people who are terminally ill may be referred into the project but that the approach to this work would be adapted as a result
- Group asked how people from Black and Minority Ethnic (BME) backgrounds were made aware of the project. Presentations were arranged to the International Women's Group and the Polish Carers' Group
- The group stated they feel that the evaluation should be set around the original small working groups so that people feel comfortable coming back together. This was agreed by the Project Facilitators

August 2017

Appendix 2



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Introduction

North Lanarkshire Council and South Lanarkshire Council Supporting People after Cancer Treatment with Individual Budgets

Introduction

North Lanarkshire Council (NLC) and South Lanarkshire Council (SLC) are working together to develop a two year project to support people affected by cancer. The project runs from 2015-2017 and is just one project funded by Transforming Care after Treatment (TCAT). TCAT is a partnership approach to improving the lives of people affected by cancer and their families.

TCAT partners are:

- Scottish Government
- Macmillan Cancer Support
- NHS Scotland
- The Regional Cancer Networks (ours being 'West of Scotland')
- Social Work Scotland
- COSLA
- Local Authorities and
- The Third Sector (such as Maggie's, The Haven)

What is the Individual Budgets Project?

The aim of the project is to work 'co-productively' with people affected by cancer as their treatment ends. Working in co-production simply means working together and this approach underpins good social work practice.

The project aims to support people in living well after having had treatment. It aims to support people to look at areas of their lives where positive differences can be made by having a small sum of money to spend.

Each person taking part will be given £250 to spend to bring about positive changes in their lives (we refer to these as 'outcomes'). Outcomes are things that cannot typically be seen such as increased confidence, increased self-esteem, gaining emotional strength (resilience).

How will the Project Work?

The project will span a two year time-frame in total with the main preparatory work being carried out up until March 2016. A quarterly Reference Group will oversee the work of project.

It is anticipated that 25 people will take part from North Lanarkshire and 25 from South Lanarkshire over the two year period.

People taking part will be asked to attend three planning sessions before being given their £250 to spend. They will be given information at these sessions about the project and they will be supported in drafting up a 'plan' to show how they are going to spend the £250, why they are choosing to spend it this way and what outcomes they are hoping to achieve after having finished their cancer treatment. The three sessions will last up to an hour each and will be:

Session 1 – introduction to the project and 'planning'

Session 2 – thinking about outcomes and support after treatment

Session 3 – developing the plan and authorising the budget

There will be one evaluation session that people will be asked back to to discuss how they have spent their money and what a difference this has made. People taking part will be asked to document how their budget was spent (this could be in taking a few photos, keeping a short diary etc).

The project will also be independently evaluated by Edinburgh Napier University.

How will People be Supported?

Those taking part may be supported at the three sessions by staff (colleagues from voluntary sector organisations, the NHS, the Councils etc).

In recognising that living with and beyond cancer can be an extremely difficult time in people's lives, additional, individual support will be available through The Haven and Maggie's should this be needed.

People affected by cancer may also choose to be supported at the sessions by a friend or family member/a carer. This project recognises that family carers are equal partners in care and though the project focuses on supporting people affected by cancer, carers will be supported.

What does this Project aim to do?

The way that social care needs are assessed and funded in Scotland has changed. Self-directed support was introduced in 2014. Social Work departments within Scotland are now working under this new law (Social Care (Self-directed Support) (Scotland Act) 2013).

The new law is underpinned by several legal principles but very much aims to improve social work practice by focussing on working with people to achieve good outcomes.

The project ultimately aims to:

- Evidence that people have increased confidence in their lives after having used the budget to direct support in whatever form
- Recognise people as experts in their own care, bringing about increased self-esteem
- To support carers as equal partners in care planning
- Work to the principles of self-directed support. These are:
 1. Collaboration (working together)
 2. Involvement
 3. Information
 4. Treating people with dignity
 5. That people are able to participate in community life

What Difference will the Project Make?

The project aims to support people taking part to bring about positive changes in their lives through using a small sum of money.

For health and social care staff as well as partners, the project aims to demonstrate what a difference people can make to their own lives when given the control to direct their own care. It will reinforce that people are the experts in their own care, it will raise awareness of wider statutory and voluntary sector supports and it will be an opportunity for learning both at a community and individual level.

A full report will be written to demonstrate the learning from the use of individual budgets and this will be widely distributed.

How to Refer?

If you are an adult and the main part of your treatment for cancer has ended in the last two years, you can be referred to the project by any professional who has supported you (eg: Cancer Nurse Specialist, GP, Social Worker, Maggie's/The Haven). Referrals can be taken by:

Gordon McComish – Locality Manager (North Lanarkshire Council): 01236 856110 or at: McComishG@northlan.gov.uk

Claire Pearson – Planning Officer (South Lanarkshire Council): 01698 455960 or at: claire.pearson@southlanarkshire.gcsx.gov.uk

If you require this information in an alternative format please contact Maureen Bridges at South Lanarkshire Council on: 01698 455787.

Please note places are limited for the project.



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Background to the Project **Why this Approach is Being Taken?**

Macmillan Values Based Standard

The over-arching approach to cancer care is based upon human rights, focussing on 'what matters' to people affected by cancer. In 2009 Macmillan Cancer Support commissioned work to research and develop a standard for cancer care services. The Value Based Standard is based on eight behaviours ensuring that people's rights are upheld on a daily basis in relation to their cancer care and recovery:

- ✓ Naming – “I am the expert on me”.
- ✓ Private communication – “My business is *my* business”.
- ✓ Communicating with more sensitivity – “ I’m more than my condition”
- ✓ Clinical treatment and decision-making – “I’d like to understand what will happen to me”
- ✓ Acknowledge me if I’m in urgent need of support – “I’d like not to be ignored”.
- ✓ Control over my personal space and environment – “I’d like to feel comfortable”.
- ✓ Managing on my own – “I don’t want to feel alone in this”.
- ✓ Getting care right – “My concerns can be acted upon”.

Following on from the development of the Value Based Standard, the legal framework in Scotland (in relation to the delivery of health and social care services) has been changing.

Health and Social Care Delivery in Scotland – a Changing Landscape

In the last few years two new laws were introduced in Scotland, which are bringing about changes in the way in which health and social care services are delivered. The most recent law is the Public Bodies (Joint Working) (Scotland) Act 2014. This is often

referred to as 'integration' and aims to offer a more seamless approach to adult health and social care delivery.

Prior to this, in April 2014 the new Social Care (Self-directed Support) (Scotland) Act came into being. This focuses on people having more choice and control over their lives *if they want to*. It applies to children as well as adults. It also applies to family carers and young carers. People have to be eligible to have their assessed needs met by their local authority to access self-directed support (SDS).

SDS is underpinned by five main principles in law:

- Involve people to say what they think they need support with in their day-to-day lives
- Make sure people are given information to make informed choices
- Work with individuals (in collaboration) in agreeing how to support them
- For people to have their right to dignity respected
- For people to have the right to participate in community life

These principles underpin the project jointly led by North Lanarkshire Council and South Lanarkshire Council.

Assessments

Social care assessments have changed as a result of self-directed support; they now incorporate 'support planning', to look at what things are important to people. Underpinning this approach is a framework, which is based on 'outcomes' (the things people have said will make a positive difference in their lives such as feeling safe, having increased self-esteem, having things to do etc).

Within the sphere of health and social care, there is now much more focus on working *with* people taking an 'outcomes focussed approach' as people have said this is important. That is why this piece of work is being undertaken.

Social care assessments fall into largely three types:

- The questioning model – this is where a professional takes the lead in assessing, usually recommending a service or an intervention based on his/her professional knowledge, skills and training
- The procedural model – this is where professional expertise is used in a bureaucratic way to decide if people fit into criteria or entitlements
- The exchange model – **THIS IS WHERE WE AIM TO BE**. This model sees individuals and indeed carers as experts in their own problems. The professional's role is about negotiating, facilitating and problem solving but through people finding their own answers drawing on their assets (good things in their lives).

So, this project aims to raise awareness of people being experts in their own lives, of knowing what a good day would look like for them and of professionals offering support *but working differently*.

Project Aims

The project jointly led by South Lanarkshire Council and North Lanarkshire Council has four clear aims:

1. That people have increased confidence in their lives through directing their own support after treatment
2. That in recognising people as experts in their own care, self-esteem increases
3. That informal/unpaid carers are supported through this approach as equal partners in care planning
4. That the five legal principles of self-directed support (outlined above) underpin this approach in supporting people to achieve good outcomes after their cancer treatment ends

Cancer Care

Within cancer care, there is a very clear focus on the use of Holistic Needs Assessments, which look at all aspects of people's lives (such as emotional needs, spiritual needs, intellectual needs, physical needs and social needs). Holistic Needs Assessments should take place at or near diagnosis and at the end of treatment.

This project aims to enhance the Holistic Needs Assessment by working with people who are recognised as experts in their own lives. This will ultimately improve professionals' knowledge and understanding of supporting people with cancer and their families/carers.



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North Lanarkshire Council and South Lanarkshire Council
Supporting People after Cancer Treatment with Individual Budgets

Project Agreement

Thank you for agreeing to take part in the project. We would like to ask you to read the following information and to sign this form if you are in agreement with the following statements:-

- I accept that by taking part in the project I must record/document how I have spent my budget of £250
- I accept that I am expected to take part in a local evaluation of the project by the Councils
- I accept that Edinburgh Napier University is undertaking an independent evaluation of the project and I will be asked for my feedback as part of this. My contact details can be passed onto Edinburgh Napier University
- In deciding what to spend my £250 on, it is my responsibility to ensure I am physically and mentally well enough to take part in the activity I choose
- I accept that in spending my budget, the Councils must be satisfied that my chosen activity is safe and legal

Signed: _____

Date: _____

Appendix 3



Session 2

Examples of Achieving Good Outcomes

The following are fictitious (made up) case studies.

1. Ann

Ann was diagnosed with a tumour behind her eye and this was successfully operated on. She has been undergoing treatment for several months. Ann is 80 and lives alone. Her family live in England and since her treatment programme has come to an end she has become more socially isolated, going out very little. The reason for this is that Ann wears a prosthesis over her eye and she feels self-conscious about this. Ann was given an individual budget to spend and she chose to put the money towards a 'tablet' so that she could SKYPE her family. Seeing them daily has increased her sense of self-worth; she is happier to be better 'connected' to them and reports feeling less lonely.

2. Sue

Sue is married with two young children. She has had breast cancer and has responded well to follow-up treatment after having had a mastectomy. Her family have been well supported by a Third Sector organisation and this has greatly helped Sue in her recovery. However, Sue's emotional health has understandably been affected since her operation and she states she feels 'low' at times and that her whole life has recently been taken over by her cancer treatment. She was given an individual budget to spend and decided to book herself and her best friend into some spa sessions at a nearby hotel for some 'pampering' and time to feel like Sue again, "rather than a patient". Sue has experienced some difficult times in relation to her looks and views the spa sessions as the start of beginning to build her self-esteem and self confidence.

3. John

John is in his 50s and he lives alone. He was widowed ten years ago and has no children. He is recovering well from testicular cancer. John has always led a healthy life, eating well and exercising but he has held down a stressful, high profile job. When he was diagnosed with cancer he states that his perspective on life changed and whilst still enjoying work, it became less important in his life. John spoke to his employer about reducing his hours as a result of the diagnosis and this was agreed. He was offered an individual budget and decided to spend this on membership to a golf club as this was something he had always wanted to do but never felt he had the time for. Joining the club gave him the opportunity to have some 'time out', to meet new people, make friends and learn new skills, thus increasing his quality of life. John now reports that he 'works to live' rather than 'lives to work'.

4. Syed

Syed is recovering from Leukaemia. He is married with a twelve year-old daughter (Fawzia), whom he is very close to. When he was diagnosed with Leukaemia, Syed and his wife chose to tell Fawzia about the illness and the treatment he would undergo. Fawzia became quiet and withdrawn seeing her Dad unwell and under-going treatment. Whilst she received support at school from the Guidance Teacher, Fawzia's reaction to Syed's illness placed added pressure on him. When he was offered an individual budget, he decided to spend this on something he knew Fawzia would enjoy and that they could benefit from as a family. Syed spent his individual budget on a pet dog (Biscuit) for her. Having Biscuit has greatly improved Fawzia's confidence as people stop Fawzia and her Dad when they are out walking him; she has started talking to people when they ask about Biscuit. Syed enjoys seeing the happiness that Biscuit brings and states that having a dog has lifted the family's spirits, giving them a new focus as Syed recovers.

'Feeling Good Plan'

Name: Ann Smith

What does a good day look like for me and people close to me?

A good day for me is having someone to talk to because I'm not feeling so lonely. It would be having someone call in for a coffee or going to the garden centre with a friend to buy plants because I like gardening.

It would be getting out of bed easily; I have some arthritis and I can take a while to get going when it flares up!

What does a bad day look like for me and my family?

A bad day's having no-one to speak to and no-where to go. I can feel very lonely in the house by myself and I get sick of the TV. I know when my daughter rings and asks what I'm up to that she worries if I say I've not been out of the house for a few days. She tells me to go out for a walk but it's not that easy and I'd like to have some company.

What would the best day look like?

The best day would be going out with a friend or having someone call by to see me but I don't really have close friends so being able to speak to my son and daughter in England would make such a difference.

I'd be feeling good and I'd have something to look forward to in my day.

This is how I want to use the £250 budget to achieve good things.

A friend of mine told me about SKYPE and I was thinking I would use the money for a 'tablet' so that I could speak to my son and daughter in England and I could see them too. I could also see my grand-children and speak to them and they could show me things they've been doing.

What difference will this make to me?

I will feel less lonely and happier within myself. I would feel closer to my family and I know this would also benefit them so I can stop worrying about them and they can stop worrying about me; I'd be less anxious. It would allow me to connect with the outside world and I'd have something to look forward to each day in seeing them even if I can't get out.

Funding Proposal Agreed by: _____

Appendix 4



Appendix 3

North Lanarkshire Council and South Lanarkshire Council Supporting People with Individual Budgets

Session 1 Outline

Welcome and introductions

Signing in sheet/contact details

About the project

Agreeing group 'rules'

Background to the project

Evaluation part 1 (core data, well-being scale, stories)

Project Agreement

Next two sessions

Follow up meetings:



TRANSFORMING
YOUR
CANCER CARE

WE ARE
MACMILLAN
CANCER SUPPORT



Session 2 Outline

Welcome and introductions

Signing in sheet

Outcomes/feeling good jigsaw

What are outcomes?

Thinking about your outcomes and using your budget

Next session

Follow up meeting:



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Session 3 Outline

Welcome and introductions

Sharing plans

Signing off

Payment details

Thinking about recording and evaluation/prompts

Evaluation session

Evaluation session meeting:

Appendix 5



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Evaluation Session

- Welcome and introductions
- Recap – project aims
- Sharing of stories/experiences of the budget/project
- Role of Edinburgh Napier University
- Mileage/travel expenses
- Focus group/interviews for those who wish to stay on

Please note the sessions will be taped unless you have expressed not to be recorded speaking

Please also have a look at the literature we have brought along



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TCAT Project Evaluation
Lanarkshire's Individual Budgets Project

Client Reference Number: _____

We are evaluating our project and are seeking your views on the difference this project has made to people who took part. By giving us your feedback we can understand your experience better and identify how we can improve the project.

Please help us by taking the time to answer these questions. Questions 1-4 are based on a scale of 1-10 with 10 (very confident) being the highest and 1 (not at all confident) being the lowest. Please circle one number that relates best to your thoughts and feelings:

Questions

1. My confidence levels have increased as a result of the project

1 2 3 4 5 6 7 8 9 10

2. The project has helped me with the management of my health

1 2 3 4 5 6 7 8 9 10

3. I feel my own expertise (in relation to my health and wellbeing) has been recognised as part of the project

1 2 3 4 5 6 7 8 9 10

4. I have felt more 'in control' of my wellbeing since getting involved in the project

1 2 3 4 5 6 7 8 9 10

Please answer the next three questions with a tick (yes/no answers):

5. The project came along at the right time for me

Yes

No

If you have answered 'no' how could we get the timing right ?

6. Was the amount of money the right amount?

Yes

No

If you have answered 'no' what amount would have been?

7. Only as a result of getting involved with the project, please tick the support you have accessed:

- Maggie's Centre
- The Haven
- Money Matters/Welfare Rights
- Carers' organisation
- Counselling
- Health services

8. In what ways has the project made a difference to your life?

9. Do you have any ideas or suggestions about how this project could be improved to support people affected by cancer?

10. What have you valued most about this project?

Thank you.

Well-being Scale

To be completed at the First Session and Evaluation Session

Client number: _____

Below are some statements about feelings and thoughts.

Please tick the box that best describes your experience of each over the last two weeks

STATEMENTS	None of the time	Rarely	Some of the time	Often	All of the time
I've been feeling optimistic about the future	1	2	3	4	5
I've been feeling useful	1	2	3	4	5
I've been feeling relaxed	1	2	3	4	5
I've been dealing with problems well	1	2	3	4	5
I've been thinking clearly	1	2	3	4	5
I've been feeling close to other people	1	2	3	4	5
I've been able to make up my own mind about things	1	2	3	4	5

“Short Warwick Edinburgh Mental Well-Being Scale (SWEMWBS)

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References

Audit Scotland (2017) *Self-directed Support 2017 Progress Report*, Audit Scotland: Edinburgh

Cook, A. and Miller, E. (2012) *Talking Points Framework*, Joint Improvement Team: Edinburgh

Department of Health (2011) *The Health Survey for England – Health, Social Care and Lifestyles* [Online] Available from: <http://content.digital.nhs.uk/catalogue/PUB09300> (Accessed 07.09.17)

Hunter, S. And Ritchie, P. Eds. (2007) *Co-production and Personalisation in Social Care*, Jessica Kingsley Publishers: London

Information Services Division (2017) *Data Tables: Cancer* [accessed 10 October 2017] at: <http://www.isdscotland.org/Health-Topics/Cancer/Publications/data-tables2017.asp?id=1982#1982>

Long Term Conditions Alliance Scotland (2008) *“Gaun Yersel” The Self Management Strategy for Long Term Conditions*, Long Term Conditions Alliance Scotland: Glasgow

Macmillan Cancer Support (2013) *Macmillan Values Based Standard – Overview*, Macmillan Cancer Support: London

NHS Scotland (2017) *Cancer in Scotland, April 2017*, Information Services Division NHS National Services Scotland: Edinburgh

NHS Lanarkshire (2017), *Achieving Excellence*, NHS Lanarkshire, [accessed 9 October 2017] at: <http://www2.nhslanarkshire.org.uk/publications/Documents/Achieving-Excellence-March-2017.pdf>

NHS Lanarkshire (2013), *Cancer Strategy – a Framework for NHS Lanarkshire 2013-2016*, NHS Lanarkshire, [accessed 9 October 2017] at: <http://www.nhslanarkshire.org.uk/publications/Documents/Cancer-Strategy-Report.pdf>

NHS West of Scotland Cancer Network (2017) *Psychological Therapies and Support Framework for People Affected by Cancer*, NHS West of Scotland Cancer Network: Glasgow

Scottish Cancer Registry Information Services Division NHS National Services Scotland (2017) *NHS Board Area of Residence – Trends in Incidence 1991-2015*, ISD: Edinburgh

Stewart-Brown, S., et al., (2009) Internal construct validity of the Warwick-Edinburgh Mental Well-being Scale (WEMWBS): a Rasch analysis using data from the Scottish Health Education Population Survey, *Health and Quality of Life Outcomes*, 7 (15)

Tennant, R., et al., (2007) The Warwick-Edinburgh Mental Well-being Scale (WEMWBS): development and UK validation. *Health and Quality of Life Outcomes*, 5 (63)

The EuroQol Group (1990) EuroQol – a new facility for the measurement of health-related quality of life *Health Policy*, 16 (3) pp:199-207

The Scottish Government (2010) *Self-directed Support – a National Strategy for Scotland*, The Scottish Government: Edinburgh

The Scottish Government (2016a) *Beating Cancer: Ambition and Action*, The Scottish Government: Edinburgh

The Scottish Government *The Scottish Cancer Patient Experience Survey 2015/16* (2016b) [accessed 10 October 2017] at:
<http://www.gov.scot/Resource/0050/00501127.pdf>