

Putting People First:

Support planning and brokerage
with older people and people
with mental health difficulties



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Introduction

This guide responds to the findings of the Personal budgets pilots evaluation, which concluded that more work was required to develop approaches to support planning and brokerage that work for all groups of people rather than just some. The guidance and examples below illustrate effective methods for support planning with older people and people with mental health problems that can be built upon by councils and other stakeholders in their local development of self-directed support.

This guide was developed through listening to the stories and experiences of older people; people who have mental health problems; and their supporters. A facilitated group of Personal budget users, support planners and others identified elements of best practice in support planning and brokerage through sharing stories and discussing what they had learned. We used the principles of Appreciative Inquiry – sharing success and learning from this.

This short report shares principles of best practice. It is specific to people's experience of support planning and brokerage. The report is not intended to be exhaustive, but instead reflects the experiences of some of the pioneers of support planning and brokerage, who have personal budgets, or who have been part of the journey.

Our work together identified 12 key principles of best practice in support planning and brokerage, regardless of whether you are supporting older people or people who have mental health problems. We start with our shared view of best practice.

A shared view of best practice

What do we mean by Support Planning and Brokerage?

The terms 'support planning' and 'brokerage' are common currency in social care but are sometimes used in different ways. Broadly speaking, within the context of personalisation, they are used to describe **the assistance that people need to work out what their choices will be, and the support required to make it happen**. For a fuller definition, see Department of Health guidance *Good Practice in Support Planning and Brokerage*, 2008.

The 12 key principles of best practice in support planning and brokerage which people identified are grouped under the following headings:

1) Support planners and brokers

- You choose
- Qualities of a great support planner

2) Information before you begin

- The criteria for signing off plans, and what you can and cannot spend your money on
- What is available locally and how much things cost
- Stories and examples of what people have tried and learned locally

3) Developing the support plan

- Pay attention to history, hear the person's story
- The person sets the pace of the planning process and chooses who else to involve
- Plan for contingencies and be flexible
- Try different ways to listen to people
- Focus on what is important to the person (not what is important to staff)

4) Sharing the support plan

- Support plans should reflect how the person wants them to look
- Good communication about next steps and feedback is crucial

1) Support planners and brokers

You choose

A key principle is that people choose who they want to assist them in developing their support plan. There are a variety of ways and a range of different people who can provide assistance in support planning and brokerage. When people have their indicative allocation information needs to be available to people about the range of local options for who could help them plan (if they want assistance).

Some people, like James, have developed their support plan with people that they already knew and trusted. James' community nurse, Ken, worked with him to develop a support plan.

James said trust was an important factor in planning his support. "It was the first time that my relationship with Ken became two way; we were working out the decisions together."

Kevin tells a similar story: Kevin had three 'interviews' with his community nurse and support planner. He said he didn't feel like he had to do very much except "tell his story." As a group, they talked about what was important to him, what was working and not working for him, and what he wanted in the future.

Other people want a support planner who has personal experience of developing a support plan for themselves or a family member.

In Barnsley older people are trained and working as volunteer peer support planners and/or brokers.

The local support brokerage team advertise for volunteers in the local paper, internet and through the local voluntary community organisation. They provide six days training on how to develop support plans and then a further four days of coaching and mentoring about different issues like person centred communication and the Mental Health Capacity Act. Avril from Barnsley's Self Directed Support Team said it was about connecting with people who've been there and got the t-shirt.

"Peer support provides a powerful collective voice to support the delivery of services and offers role models to others who might feel nervous or worried. You're building a social relationship model rather than one where professionals are trying to sell a service. We are all people at the end of the day. If you're allocated a worker, and you've had no choice in who they are, you may not like them for whatever reason. This can affect the actual outcomes within the support planning process – it can be dictated by how comfortable you are with that person."

Local Barnsley resident Frank jumped at the chance to volunteer as a peer mentor straight away. "You see, I can tell you **what it's like** to look after someone who has dementia, not just tell you **what it is**. There are lots of older people, retiring, who get into a little cage of their own, but who want to get out of it, and want more from life. So now I help people. That's what I was born for – at least that's my attitude anyway."

Centres for Independent Living can provide local assistance from experienced disabled people.

John's care coordinator, a support planner from the local Independent Living support planning service, and his key worker at the residential care home, worked together to enable him to write his support plan.

In Lancashire and North Somerset providers are involved in helping people to develop

their support plans. In North Somerset, where people don't want to change their provider (e.g. for support at home), the provider is allocated extra time to enable them to work with people to develop support plans.

Qualities of great support planners and brokers

Great support planning and brokerage requires some important qualities from the people involved.

The group thought that good support planners and brokers are:

- Committed to the person they are planning with
- Values driven
- Flexible – they work at the person's pace
- Great listeners
- People with a 'can do' attitude
- Solution focused
- Creative – they really can 'think out of the box'
- Knowledgeable and informed (see section 2)

These qualities are not exclusive to a particular job role, for example, not every care manager, community nurse or provider automatically has all of these attributes. Often services have not encouraged or rewarded creative solutions based on 'thinking outside of the box' in their staff. The importance of values and beliefs in effective planning is supported by research, where the values of the facilitator were found to be the

most important factor in successful person centred planning.

Shelly, a support broker for older people, was committed to helping Mrs Andrews and her carer find a flexible solution to their support needs. Shelly and Mrs Andrews were working on the fourth version of Mrs Andrews's support plan. They had gone through lots of different scenarios and options to find the right mix – like agencies, personal assistants and different ways of managing the money. Through that process, they discovered that Mrs Andrews's carer hadn't taken any of his respite. Shelly explored why this was happening and discovered it was because the carer thought he had to use it all at once. Because Mrs Andrews didn't like leaving the house, it meant he didn't either. With Sally's help, they've found a solution where he can take his respite as 10 separate days during the year. He now uses this time to do the things he likes to do, like going to the dogs or horse racing. It's made such a difference because Mrs Andrews is happier, and he feels content she's got the right people to look after her while he's out.

Julie's support planner helped her build her confidence through listening well, by flexibly working at Julie's pace, and intentionally working in ways that built her confidence.

Julie left home and lived on the streets. She eventually moved back home with her mum and dad but they found it difficult to help her.

She had a residential placement but she wouldn't go as it wasn't what she wanted and the people working with her didn't know what to do.

"When I first met her at home, Julie only looked down and never at me," said Carol. "But as we chatted she started to look up and said she was prepared to try the support planning."

Carol arranged for a support worker from the local Independent Living Centre to help Julie with her support plan. They dedicated time to carefully listen to Julie and slowly explain to her the processes involved. Julie blossomed: she was being asked her opinion and her feelings about what was working and not working in her life. Previously, she was told she couldn't do things – for example – that burning things on the stove meant she couldn't cook.

The support planner took time to listen to Julie so that the support planning process contributed to developing Julie's confidence.

"Initially Julie didn't want to do anything, but now she decides what she wants; books it and pays for it herself. Julie's plans are to go into voluntary work and move into independent living as she is now feeling more confident and able to move away from her mum and dad.

Carol said, "We had a letter from her parents to say what a fantastic thing personal budgets were and how it has helped their daughter. Julie is now more confident, taking part in conversations and giving her opinions."

2) Information before you begin

One of the qualities of good support planners and brokers is that they are knowledgeable. Here are four areas about which people need information before they start developing their support plan. The person with the support plan and the people helping to develop it both need this information.

Understand the sign off criteria and what you can and cannot spend the money on

Councils can look to provide clear, unambiguous information about the criteria that they will be using to sign off support plans. Support planners and brokers must be able to enable people to develop plans that reflect the information requirements of the council.

Similarly, councils can provide clear, simple information on what people can and cannot spend their individual or personal budgets on.

Knowing what to do or who to ask if anything is not clear is also important, right from the start.

Know what is available locally and how much things cost

Many councils and Voluntary Agencies have resource directories (for example, Plymouth Resource directory for older people).

For people to be able to make informed decisions about how to spend their Personal

budget, they need to know what exists as well as how much it costs.

Some forward thinking councils and partner organizations have invested time in mapping out what is available in the local community and finding out what services and supports cost. Barnsley have produced some information on what services are available and what they cost to people as they begin support planning. One service is called 'Pay Packet' and this has been helpful for many older people in managing their Personal budget.

Using an organisation to pay the wages of carers made a big difference to Edith and Ian. They use 'Pay Packet' to manage the Personal budget. With their carer, they fill in the time sheet every week and then every four weeks they send it off and a copy of the wages is sent to Ian.

"I don't have to do a thing. There are always some people I can call upon... local people if I need help."

In Barnsley there is a dedicated worker who is community mapping all areas of Barnsley and feeding that information into their Voluntary Action Barnsley (VAB) website. It lists details for services available locally, for example, where the scouts are or the local fishing club is. But it's not just about services – other community groups can add events too www.vabarnsley.org.uk

Stories and examples of what people have tried and learned locally

Hearing what other local people have tried and learned can be a source of inspiration and information to others who are developing their support plans.

Councils can invest in ways to support people to record and share their experiences. Person centred reviews of support plans are a practical way of gathering this information.

In Bath and North East Somerset they are sharing creative stories and examples through using different media, for example through service user groups and video.

Barnsley have a story telling framework which includes written stories and DVDs. People explain what their life was like before they had their support plan and how it has since changed. The stories also give people ideas on what they can spend their money on. Barnsley share these stories on their council and local PCT websites. They also talk about them at local and national conferences.

3) Developing the support plan

Having chosen a support planner or broker to assist you, and with all the relevant information to hand, the process of developing a support plan is crucial to the

quality of information it contains and outcomes achieved.

Pay attention to history, and hear the person's story

One way to get started with a support plan is to hear the person's life story, and get to know the person on their terms. Sometimes this can provide important information about interests and activities that the person used to do, that they may want to explore again.

Frank always asks the person he is helping whether they mind if he asks a few personal questions. "When I approach people, I like to open them up straight away and show them I'm someone who's friendly: I'm not an official, I'm one of them. One gentleman, who was very ill, told me about his work and how it led to his divorce and emphysema. But we also talked about how he loved to go caravanning all over England. He lived on his own in a bungalow with support from his brother and Personal Assistant. He only had his Personal budget five or six months before he died, but I helped to make his life a little bit better."

A support broker in Barnsley was sitting in Mr Butler's front room. He noticed a picture of an army unit on the mantelpiece. They talked about the picture and found out Mr Butler had served in the army. Through that conversation, the support broker was able to find out that Mr Butler was entitled to two

weeks holiday per year with the British Legion as well as membership, giving him access to clubs and other people who had been through similar experiences.

Steve lives in a rural area and had been diagnosed with a schizophrenic illness many years ago. His family are farmers and shooting and fishing is part of their life. Steve spent his time at home not doing very much and either staying in bed or sitting in the house smoking. In developing Steve's support plan with him, Ken wanted to find out what Steve used to do. He found out that an OT had previously worked with Steve and talked to him about going fishing when he felt agitated. Steve's support plan included going fishing again.

Nan, who lives in Sheffield, had always lived independently and actively as a young woman. Even though she lost three of her own children, she opened her home to others who didn't have parents. In her support plan, it was important to acknowledge that Nan wanted to do things for herself, like she'd always done, while freeing up the time her daughter Anita was spending on looking after her. Nan said: "I had to call on Anita to do a lot of things for me, that I could have been doing, should have been doing myself." Now Nan has a personal assistant – Rachel – to support her every day. "Anita showed Rachel everything about Nan, including how to give her medication. "And that sets you free," Nan said to Anita, "That's how I want it."

The person sets the pace

The person sets the pace in how the support plan is developed and also the breadth of information in it.

James and Ken had a 2 hour session together every fortnight. They focused this time – time that they used to spend together anyway – on developing James's support plan. This pace worked for James.

Working at the person's pace also helps them to see the money in the context of their life. Although support plans focus on how someone's budget will be spent to achieve their goals and agreed outcomes, some people want to use this as an opportunity to think about the whole of their life. The plan captures the information needed to be signed off (but it is important for this other information to be recorded as well, so that the person has a reminder of these wider concerns). Other people only want to think about and share the information that directly relates to their personal budget. Both of these things are possible.

Some people will initially seem cautious in the plans they make and the risks that they are prepared to take. Over time, particularly when they hear from others about what has worked for them, they may be more prepared to make different and perhaps bolder decisions. Going at the person's pace means both in the content of their plans as well as the time taken to develop them.

Frank says "It's a matter of persevering, concentrating and not rushing into any questions. I keep the conversation rolling along, and if they're not happy or don't understand something, I'll put the question in a different way. It's important to break the monotony. If you constantly ask questions, people get bored."

Avril said that the actions on the support plan don't have to be big 'wow' things, just small creative things.

Mrs Coombes needed a lot of help with personal care. She previously had major mental health issues and had not left the house for 12 years. Her daughter lived next door, but the informal caring role was placing a lot of pressure on her, as she also had to work full-time. Through the support planning process, they decided to hire a personal assistant to help build the lady's confidence. The first PA they found wasn't the right match so they found another. The lady was tearful because she thought it wouldn't work, but they worked together, and gradually her confidence grew and grew. They're now out and about, not just locally, but also take trips to a big shopping mall. It wasn't a big 'wow' change, but it made a lot of difference."

Try different ways to listen to people

Good support planners explore different ways to hear from people. This can include talking together whilst you are doing things together.

Avril has had great success talking about what is important to the person and what is working and not working for them whilst she is painting the persons fingernails or looking at magazines together.

Can you imagine developing support plans whilst:

- Shopping?
- Gardening?
- Doing housework?
- Cleaning the car?
- On a train or bus?

This is where the qualities and skills of the person doing the support plan also come into play.

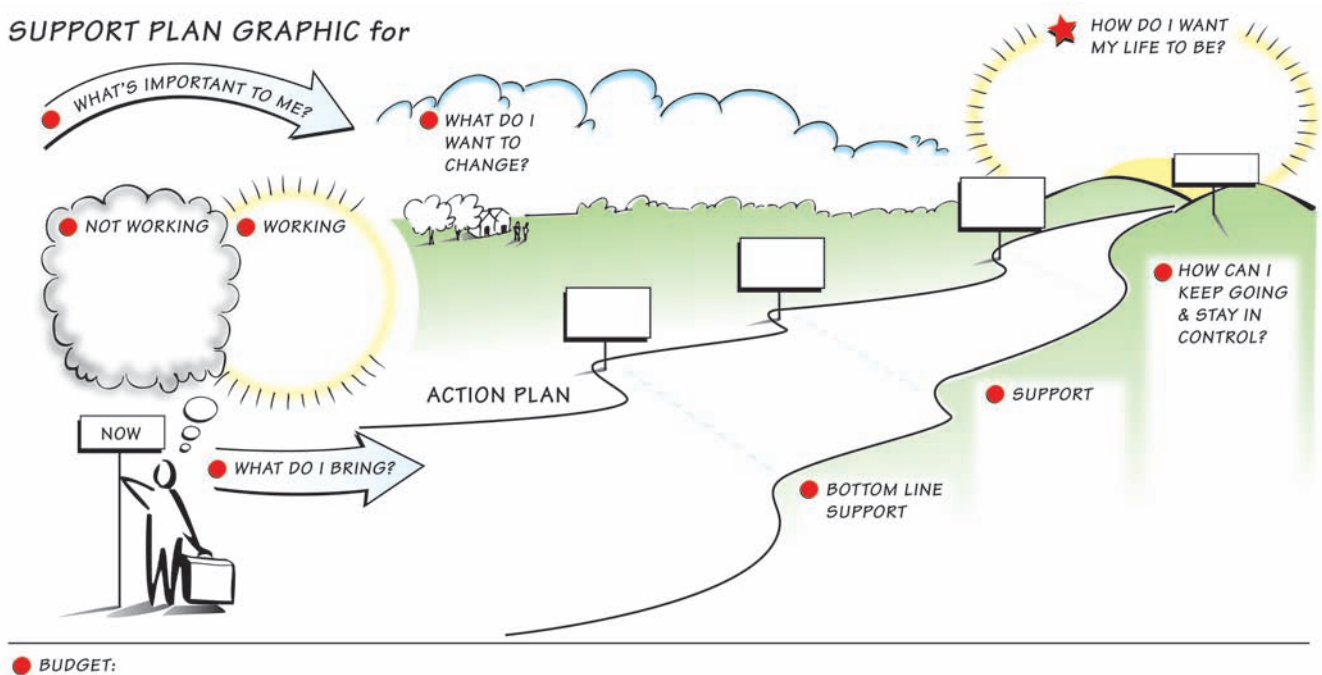
As an older person with experience of support planning and using a budget himself, Frank feels strongly that people will open up to him in a way that they might not to a professional: "I'm instantly familiar and can hit it off in a way that might not happen or take longer with a paid person"

In Sheffield older people developed their support plans as part of a small group, working together over 2 days as part of a process called 'Planning Live'. The group used a booklet based around Sheffield's support planning criteria. People used this to develop their support plan and used a large graphic template. Nan (who was 94 years old) enjoyed using the graphic and seeing the visual representation of her life. There were four older people and their families who over two days spent time thinking, talking and developing their support plans.

Jeanette Thompson, personalisation lead for Sheffield said,

"Nan loved having the opportunity to spend time focusing on her life and having this represented on the graphic". Nan's story can be found under the stories section of this report.

SUPPORT PLAN GRAPHIC for



Focus on what is important to the person (not what is important to staff)

A key to person centred work, and therefore to support planning is to clearly separate what matters to the person from their perspective, and what matters to others including staff. Great person centred planning focuses on what is important to the person. It does not neglect what is important for them to stay healthy and safe, and this is approached within the context on what matters to the person, seeking a balance of important to and important for.

Sarah has an Obsessive Compulsive Disorder. She loves cats but her house used to be in a 'terrible state'. Support workers wanted to help Sarah get it cleaned but she couldn't bear people moving a single chair. The local Independent Living service was able to organise support with Sarah at a time that worked for her and at her own pace. When developing the support plan, her team spent time explaining that it wasn't about what they wanted, but what was right for her.

Sarah geared her plan around small things like buying a filing cabinet to put her possessions in. She wanted a new carpet but took a while to get to that point. While doing so, she began to think about her appearance and asked if she could go to the hairdressers and it was during this time she began to think that she did need her house cleaned.

There was a stage in her life when Sarah wouldn't let the gas man in to take a reading,

but by the time of her review, ten months later, Sarah had had the whole house cleaned with new carpet laid, new cabinets in the kitchen and a computer.

The support planning process helped Sarah think about how people responded to her, reflect on how she felt and just how much she had achieved. The support planner had stayed focused on what mattered to Sarah, and this helped build her confidence to make changes herself, at her pace.

Angela is fiercely independent and has taught all her working life. After retirement, she volunteered to lecture at the local university. The most important thing for Angela is to have a support plan that recognises she is devoted entirely to this and wants to remain independent and in her own home for as long as possible. . With the help she is receiving from a live-in carer, another carer and an agency, Angela feels she will be able to keep well and have the confidence to carry on teaching her classes.

Plan for contingencies – when people are well and unwell

Great support plans include planning for contingencies.

Kevin's support plan included a section called a "keeping safe plan". This covered how he could address problems if they arose, for example, whether the planned activities could

result in an increased risk of mental health problems or additional stress.

The support plan included how he and others would know if he needed more help and how he could stay in control if his mental health got worse.

Pauline's goal was to stay out of hospital and move forward from the unstable situation she felt she was in. For eight years, she received direct payments, meaning she spent only six weeks in hospital each year compared to the many months prior to that.

Her new goals were modest: to move into her own home and get a job. She worked out a support plan based on what many may describe as a fluctuating condition. Pauline has psychosis, which means she sees things and becomes unable to manage for herself, but at other periods, she is really well and able to carry out a responsible job.

For some people, this instability means they live a quiet life waiting for an episode to occur. Pauline instead planned for the difficult period so she can be prepared. When she is well, Pauline only uses two or three hours of support per week, but when she becomes unwell, she has up to 24 hours of support. Importantly, she has a permanent support worker who does as few as three hours or as many as 20 hours per week.

Pauline's weekly amount as a direct payment has been worked out over the years. Now she has also appointed someone else who can spend on her behalf. That's because the time

she needs to spend most of the payment is usually when she is not able to manage it herself. The funds build up in her account for when she really needs it.

Tony has split his support plan into two parts – Part A and B. When he's well, he doesn't need much support, but when he's unwell, he needs a lot more support. His plan sets out examples of when a particular event occurs and the kind of support he needs to address it.

Support plans cannot cover all eventualities, and brokers have a role in helping people manage when things change, as they did with James and also Joe's life.

"Getting £4200 is a bit surreal," James said. The car was agreed in my support plan. It blew its head gasket at the end of the year, which I couldn't have predicted, but I was able to fix it as I am a qualified engineer and used some of the budget to replace the engine. It will keep me going. From this we both learned we needed to think about planning for contingencies."

Joe is a young bloke who had been an extraordinarily fit man who used to work as a personal trainer. He had an acute episode and as a result, found himself supported by the early intervention team. He developed his support plan over three or four meetings with his broker, where he could think about what he would like to do.

Rather than striking out on a new path, Joe

felt he would like to regain the areas he had excelled in. He wanted to use his budget to rejoin his old gym where he had friends and felt safe. It was quite expensive and different to what he would have received if he had gone through his GP. However Joe said he didn't want to go to a gym that "catered for people who spent most of their time chatting!" For him, it needed to be "a serious gym with weights". He also planned to work with other people who had mental health problems to "give something back".

Joe was doing well but then fell and broke his leg. The broker negotiated Joe being able to freeze his gym membership for two months whilst her recovered.

Tony developed his father's support plan. His father had Alzheimer's Disease, and the front cover of the plan had a wonderful photograph of his father.

Frank created his wife's support plan. She had dementia, and the photograph on the front was a celebration of who she was, and how beautiful she looked when they used to go dancing together.

Mathias was planning to spend some of his budget on his own lap top. He presented his support plan in powerpoint

In Norfolk people are shown a range of different ways that plans can look. This includes a mind map and graphic examples of support plans.

4) Sharing the plan and follow up

Support plans should reflect how the person wants them to look

The way that a support plan looks should be an extension of how the person wants to communicate information about themselves. There are no prizes (or extra money!) for creativity, it is simply ensuring that plans look the way that people want them to...although a few pages of text is just as important as a DVD set to inspiring music.

Good communication about next steps and feedback is crucial

The individual budget pilot evaluation described how frustrated people felt about the length of time it took to sign plans off and that they were not kept informed of progress.

It is crucial that people know what the sign off process is, whether this is the responsibility of an individual or a panel, what the timescales are and what the procedures are for appeal or complaint.

Good practice recommendations

These recommendations reflect the views of the working group which produced this document. They cover what would need to be in place for more older people and people who have mental health problems to benefit from great support planning and brokerage, in order to use their personal budgets to make the changes that they want to see in their lives.

Councils should consider:

- 1)** Building capacity for support planning so that people can have a choice of who assists them – including by investing in local User Led Organisations and making Peer Supporter available.
- 2)** Before people get started with their support plan, ensuring that care managers provide clear, written, local information on:
 - The range of people who could help them and how to contact them
 - The criteria for signing off plans, and what people can and cannot spend their money on
 - What is available locally and how much things cost.
- 3)** Intentionally investing in gathering local stories and examples of what people have tried and learned locally, and making these available in different ways for people. Ensuring that everyone offering support planning assistance has stories of what works to share with people.
- 4)** Investing in training and regular support for people providing support planning assistance, to ensure that people know how to:
 - Pay attention to history, hear the person's story
 - Work with people at their pace
 - Plan for contingencies and be flexible
 - Try different ways to listen to people
 - Focus on what is important to the person (not what is important to staff)
 - Help to create support plans that reflect how the person wants them to look.
- 5)** Having agreed standards for how long it should take from the completion of the support plan to a decision on sign-off of the plan and the money being released. Communicating these standards, helping people to achieve them, and reporting publicly on progress.

Appendix – Stories

John's story

John is “young at heart”. He loves socialising and going to see shows including Elvis impersonators, rock ‘n roll performances and comedians like Jim Davidson. However, he can suffer very low moods leading to depression. John has been living in a residential care home in Ipswich for 35 years but eventually said he wanted to live more independently.

“I wanted to be free, cook when I want, come and go when I want, be my own boss.”

Together with the help of his care coordinator, the local Independent Living support planning service, and his key worker at the residential care home, John started to write his support plan for a personal budget. They talked about the things he liked and what was working and not working in his life. They also talked about what John wanted to happen and where further information or help might be available.

John described wanting to live in his own home, but where he didn't have to worry or be alone for too long. It was important he kept in touch with his brother and had respite to lift his spirits. He said he was nervous about living by himself and being able to sort things like his washing machine and cooker.

However, once John and his support team talked everything through and worked out how they could make it happen, he started to get excited.

John's personal budget now buys in the services and support he needs to live independently, organise and maintain his budget, and remove some of the worries and loneliness. He employs two personal assistants and a support worker. The Independent Living service helped with recruitment and doing the wages, but John pays his own rent and keeps all the files.

“I'm living by myself in my own bungalow with kitchen, wet room and lounge. I have wardens to help me feel secure and there's a pull cord in every room. We all get on very well. My support worker is marvelous. She comes in every Monday and Friday and does the washing and drying.

“I was worried about managing on my own but it's all straight now. The telephone and electric bills are paid by direct debit. I'm happy to pay the bills. I'm a free man now. Not institutionalised. I can do what I want now and no one can tell me what to do.”

This summer, John is finally going to visit his brother who lives in Southend. Next year he hopes to visit Majorca.

Kevin's story

Kevin, from Norfolk, is an active man who loves the great outdoors and identifies his hero as Ernest Shackleton, the great Antarctic explorer. For 17 years, Kevin has experienced major episodes of paranoia and was diagnosed with schizo-affective disorder. This has had a big impact on his working life, leading to cycles of joblessness, homelessness and hospital stays. He would make a full recovery and return to work, but things would spiral, either from something going wrong in his job or stress in his personal life, and the cycle would start again.

Following the end of his marriage last year, Kevin found himself at the start of another cycle and his employment ended a few months later. At that point, his community mental health nurse spoke with him about personal budgets.

Together with a representative from the local Independent Living support planning service, they started working on a support plan. Kevin attended three interviews and said he didn't feel like he had to do very much except "tell his story." As a group, they talked about what was important to him: keeping well and only using mental health services if he is unwell, and managing his wellbeing through his social and work life.

They looked at what was working in Kevin's life – so things like his relationship with his care coordinator and his family – and what wasn't working. He described his love of cycling and making people aware of mental

health problems. He also said that social interaction, occupation and routine from work helped to stabilise his mood. They talked about what could be achieved with his personal budget and explored the idea of self-employment – providing mental health and cycling mechanics training – and the things Kevin would need to make that happen.

"Not working and living a typical service user lifestyle is something I can't bear," he said.

Kevin's personal budget now covers some of his business costs and allows him to do a trade qualification as a cycle mechanic. There is also money set aside for respite if things get too much (it has been agreed he will stay with a friend who owns a farm) and a contingency fund for emergencies and other needs.

A "keeping safe plan" was written, which considered all the risks of implementing the activities described in his support plan including:

Whether the planned activities could result in an increased risk of mental health problems or additional stress.

Whether Kevin would be able to spend his personal budget in the way they agreed.

Whether there were triggers to recognise when he needed help and how he would stay in control if his mental health got worse.

At the final interview, Kevin met with "a chap at the council" who assessed his financial situation and that was where he found out his personal budget would be approved. The whole process took less than a month.

Kevin said he would definitely recommend support planning to others. "At first I was a bit cynical," he said. "If I'd been more sure I was going to get something out of it I might have been a bit more enthusiastic. But you need to have patience and it was worth it in the end." His package will be reviewed in ten months time. "Hopefully my business will help me earn a living and I won't need a personal budget for that sort of thing. Maybe just for respite if things get too much."

Shirley's story

Before having an Personal budget, Shirley's life was "very institutionalised". She suffers a chronic health condition and used to have no choice over the type of care she received in Barnsley.

"Nothing was flexible," Shirley said. "A carer couldn't do anything for me other than the things that were laid down by the rules. She couldn't do any medication... she didn't understand my illnesses and she could only come at specific times. There were no outings... we didn't have any talk or chat. We didn't have any interests in common at all."

Now Shirley has chosen her own carer, who is "brighter and much more knowledgeable". Her daughter provides support with filling in the forms and keeping the paperwork in order.

"Life is much pleasanter now... I know that she understands things, and gets on well with the rest of my family. She anticipates what needs doing and has made an effort to learn

about the different aspects of my health... It's nice to know that somebody else understands and can take over the responsibility of looking after my medication and all aspects of it if I am feeling very ill."

Shirley said having an Personal budget and choosing her own carer made a big difference to her life.

"I'm much more relaxed and I'm more confident. Although my chronic condition has worsened, which was inevitable anyway, my actual health and well-being is much better. I haven't had to see the doctor or have any emergency admissions to the hospital... I have a very good GP practice and a community matron. Everybody works together (and) supports each other. So I think it's due to a lot of factors but mostly because of the control I have over my care."

Shirley recommends people shouldn't be daunted by the paper work of an Personal budget.

"It is much better for you than care put in place by someone else," she said. "It's not difficult at all and once you have the initial paperwork up and running, it's no problem... It's very easy to understand and there is always someone who can help you."

Edith's story

Edith lives with her husband Ian in Barnsley. Both were tired of having so many different support workers sent by the agencies who supported them.

"It wasn't a very good situation," Ian said. "They were only here for maybe half-an-hour at a time, and they kept changing the people coming... Eventually I told them I was fed up with the whole system and to not send anybody else again."

That was when Ian found out about Personal budgets.

"They told me about this new scheme and we said we would try it out... and now we find it's far superior. The difference is amazing. We now have the same girl coming to us everyday... She does everything for us that needs to be done in the house, leaving nothing for us to do later when she goes. We are very happy with the situation."

Edith and Ian use 'Pay Packet' to manage the Personal budget. With their carer, they fill in the time sheet every week and then every four weeks they send it off and a copy of the wages is sent to Ian.

"I don't have to do a thing. There are always some people I can call upon... local people if I need help."

Ian has said the whole process has made a difference to both their health and well-being and is "definitely worthwhile".

"I don't have the worries I had before. I feel better knowing someone is coming and that I can depend on them to do what needs to be done. I think Edith is better because it's the same girl every time. Anyone who is thinking about (Personal budgets) should go for it."

Edith agrees: "She cares for me very well. I like to see her and I like all the things she does."

Marion's story

Marion has two grown up children. Before having an Personal budget, she was receiving support from as many as nine different people in one day.

"It felt like they were here just because it was a job for them. You've got no privacy... no dignity left. Altogether it weren't nice. I used to dread it when it was time for them to come because you didn't know who was coming. Then you have to explain yourself and why you're in this position. It's degrading really. One minute I got so annoyed I said 'I'm going to put a piece of cardboard around my neck saying that the bottom doesn't work but the top does'."

Eventually, Lorraine from her social services department spoke to her about Personal budgets.

"I'd been having all these girls come in so I said yes, I would like to try it and I'm really glad I did. It really made a big improvement. You are in control more."

Marion now has four carers who work together to provide the support she needs.

"It's like a little family now. We can all laugh and joke. It doesn't feel medical anymore. They are ever so good, they do everything for me no matter what. You don't have to ask

half the time, they just do it. It just feels like they care. They have to do all these personal things, clean you and it's not nice, but they talk over it and make you feel... what shall I say... not as embarrassed. It's a lot nicer."

Marion said it was a lot easier to manage her Personal budget than she initially thought.

"I got a bit worried. I thought 'no, I can't do that, it's too much'. But I have this 'Pay Packet' and they will do your income tax and your pay-as-you-earn, so you have no worries on that score. All I do is get the time sheets off the girls; my daughter then sends them up to Pay Packet. They have to be in by Tuesday and the girls get their money paid into the bank on Thursdays. My daughter keeps everything in the file so it's all straightforward."

"It's made all the difference in the world. Really I'm happier, it's pleasanter... I have my four carers who are really helpful. Now I've got my daughter and my son who do things between them, so everything works out lovely, a lot nicer than the agencies... They all understand and I appreciate them, I really do."

Angela's story

Angela is entirely devoted to teaching and describes herself as very intellectual. "I worked full time as a lecturer until I retired... but I couldn't bear not going on – not for the money, but for the job satisfaction.... Now I work as a volunteer lecturing mature students twice a week at Huddersfield

University in literature and psychology." In order for Angela to keep on teaching, she needed the confidence to do so and this involved keeping well. Angela used to pay privately for her own care, but her health took a downward slide after a series of falls and she needed more extensive care.

Before Angela had an Personal budget as a direct payment, she went into a residential home to have some rehabilitation. "I felt like a fish out of water intellectually. It was not suitable. My health started to get really poor and I felt sad and lonely".

Her social worker arranged a visit from Tracey, a support broker from the local direct payment support service. She visited Angela at home and explained that developing a support plan was part of the process for getting an Personal budget. Over the course of three meetings, Angela described everything she wanted in the plan. Because her eyesight wasn't good, Tracey wrote down everything Angela said and went away to type it up.

They then met again so Angela could read the plan and agree to things or make amendments. Once that happened, it was sent back to the social worker at the council for sign-off.

In the support plan, they specified that Angela's Personal budget would go into a separate bank account and would be used to pay for an agency worker to supplement the support she already received from her live-in carer who works 8:30am – 2:30pm each day. The agency worker comes in when Angela

decided she most needed it: 6pm – 9pm, seven days per week to provide personal care and practical support including meal preparation.

“Having help is everything for confidence and when I see someone coming out of the bedroom door, that is nice, that is useful.”

Angela will review her plan with Tracey in 12 months time but if her condition was to deteriorate, or she felt she needed more help, they can arrange to make the review earlier. She said that with all the help she is receiving, she feels that she'll be able to keep well and carry on teaching her classes. It means she is living the life she loves and remaining independent in her own home.

“Having a direct payment and purchasing my own care has really made a difference to my life. I would describe it as a lifeline.”

Frank's story

Frank looked after his wife Betty, who had dementia, before she passed away in December 2007. “I went through getting an Personal budget with my wife. We only had it ten months and before that, I had to do everything for her.”

They went through the support planning process with a broker that was organised by the council. Frank said he didn't mind the process and he had to speak on behalf of Betty. He spoke all about their life and their interests in caravanning, photography and

ballroom dancing. Eventually they received support from two personal assistants in the morning, and two at night.

“The money wasn't for willy nilly spending. It was about money for keeping us healthy, happy, content and safe.”

Today he lives independently in the big house he and Betty shared – but he now volunteers as a support broker for Barnsley City Council. “What happens you see is you get to a stage... you and your wife, married for 58 years, together for 61... that's a long time. Then being on your own... I just had to get out.

“It's a nice way to help, going around to peoples' front rooms and talking to them. I worked in my wife's hairdressing salon for 15 years and was also an MC for ballroom dancing for 20 years – talking to people is no problem for me!

“You see, I can also tell you **what it's like** to look after someone who has dementia, not just tell you **what it is**. There are lots of older people, retiring, who get into a little cage of their own, but who want to get out of it, and want more from life. So now I help people. That's what I was born for – at least that's my attitude anyway.”

Frank is based in a local community organisation called Arena. They advertised for volunteer support brokers and he undertook six days training and a mentorship programme.

“I did all the admin (for the Personal budget) myself, but now I'm a support broker, I know there are hundreds of people out there who

have no idea how to do it. People are really eager to ask me questions and I give them advice as best I can. It's a brilliant idea and that's why I got involved."

Frank says that being a support broker is all about having the will and attitude to do it. "You've got to be able to converse, have good knowledge, and be able to talk about lots of different things. You need to make it easy for people and that's how I'm being trained. Professionals talk in their language and ordinary people can't understand it. I'll keep on talking as long as they want to talk. I'm 88 years old. When talking to young people, they don't seem to have a grasp on how to approach older people, but us old people, well, we are all so simple and easy with each other."

Support brokers also need to get personal.

"When I approach people, I like to open them up straight away and show them I'm someone who's friendly: I'm not an official, I'm one of them. One gentleman, who was very ill, told me about his work and how it led to his divorce and emphysema. But we also talked about how he loved to go caravanning all over England. He lived on his own in a bungalow with support from his brother and a Personal Assistant. He only had his Personal budget five or six months before he died, but I helped to make his life a little bit better."

Frank says it's important to go at a pace set by the person who the support plan is being developed for.

"Time doesn't come into it. It's a matter of persevering, concentrating and not rushing into any questions. I keep the conversation rolling along, and if they're not happy or don't understand something, I'll put the question in a different way. It's important to break the ice first by talking about something else, like holidays, or the war as it helps to break the monotony. If you constantly ask questions, people get bored."

Frank is also helping to evaluate Personal budgets in his area, seeking feedback from people who have gone through the process and what they thought. "I'm going around and taking a survey on what's right, wrong, what's suiting them, what's not and if there's anything that can be improved. I've over 100 people to see. Already done 10, and another three next week. All the people have different stories and I'm thoroughly enjoying it."

Nan's Story

Nan is 94 and has always been very active. When she lost three of her own children, she opened up her home to other kids who didn't have parents. Now Nan can't use her legs the way she used to. She is also deaf and registered blind.

Before Nan had her Personal budget she just sat around all day. Her daughter Anita said she could see her mum was miserable. "One day I asked her, mum, are you happy? And she said, 'no I'm not'. She's still very active in her mind, and she'd love to do everything she used to."

Nan said she felt “frightened, lonely and fed up”. “I’m just sat, doing nothing. I felt I wanted to do things, that I could do it. Up here (in my head) and down here (my body), they don’t grow up together... I’m not ready by a long way to have ‘had it’.”

Even though Nan lived with Anita, she still felt lonely. “I couldn’t see what Anita was doing in the kitchen, but I thought to myself, gee, I’d love to be out in that kitchen, doing that, but instead, here I am on this settee... that’s not me.”

Anita said she was finding it really hard. She couldn’t leave Nan, but still had to look after other members of her family. Everyone was always calling on Anita to help. They only had three hours of help from an agency per week, and that was barely enough time for Anita to get down to the supermarket.

Nan said: “I had to call on you to do a lot of things for me, that I could have been doing, should have been doing myself.”

Nan and Anita took part in a “Planning Live” workshop in Sheffield with other older people and their families. Over two days they put together their support plan, with members of the group encouraging and supporting each other. Nan decided to use the graphic template to start her support plan, and loved being able to see all the information on one big sheet of paper.

Now Nan has a personal assistant – Rachel – to support her every day. “She’s like a sister,”

Nan said. Anita showed Rachel everything about Nan, including how to give her medication. “And that sets you free,” Nan said to Anita, “That’s how I want it.”

With Rachel’s help, Nan says she feels like she’s 49 again. She can wash the pots and do her gardening: something Anita said she’s always done. “The outside of her home is as important to her as her inside.” Nan is also planning a holiday. She didn’t want to go on holiday with Anita and her husband, because she wanted to be able to do her own thing. “You go your way, and me and her go our way and we’ll meet up when it comes to meal times.”

Nan says she is a lot happier now and Anita thinks her mum has a new lease on life. She said Rachael has not just set Nan free from her old age, but has also helped Anita have more of a life too. “Before, I’d have to wait for Tony to come home and sit with Nan before I could go anywhere. Now with Rachel, I can just go and do it. We are very, very happy.”

Nan said she doesn’t ever want to go into a nursing home. She wants to stay in her own home where she knows where things are and she can see her family.

“Everyone has to get old, but some can get there better than others. Why be miserable?... If I could walk, I’d go directly to other old peoples’ front door and give them a good talking to myself.”