

Self directed support and support planning

Self directed support means having the support you want, the way you want it. A support plan is one way to describe how you want to live, how you want to be supported, and how you will spend your money (your own funds or an individual budget).

Derek is taking steps to make sure he has the support he needs in a way that makes sense to him.

Derek Hurst

Derek is 72 and lives in a care home in Portsmouth. He worked with the manager of his home, Kathryn to think about his life and his support.

Derek uses a wheelchair, following a below the knee amputation which restricted his mobility and confidence in getting out and about. He has since lived in local authority care homes (a number of years) and moved to his current home in 2001. He was born in Gosport, and like many local people was in the Navy between 1938 and 1962. After leaving the Navy he had many varied jobs including working as an electrician in a local factory, as a security guard and a driver.

He first moved to a care home following a serious accident, when his leg was severely burned in a fire at his flat, where he lived alone. When Derek did not turn up at his local pub as usual, the pub's landlady went to check that he was ok. Derek says he only remembers waking up in hospital - the landlady had found him and called an ambulance. He often says "she saved my life". One leg was



amputated, and he was told that he wasn't strong enough to have a prosthetic limb, so he now uses a wheelchair.

Derek's day to day life in the care home

Derek reads the newspaper everyday and watches television, enjoying snooker and quiz programmes. He particularly likes the company of a female resident with whom he sometimes shares morning coffee. He likes his room, and wants to stay living where he is. He gets upset about losing his leg, and says he sleeps a lot during the day because he is bored.

The first thing that Derek wanted to change was to be able to move more easily between his wheelchair and his bed. Kathryn said that she had no idea that this was important to Derek and she arranged for an OT to visit him, and show him some safe methods for doing this on his

own. Afterwards, Derek said he was finding this much easier, and the staff in the home said they did not have to help him so much.

His second goal was to return to the pub where he used to drink, because he wanted to see the landlady again, which he did after much discussion and some initial anxiety on the part of the care home and to some extent the pub landlady. Following a successful first visit - where Derek was delighted to be able to thank the landlady properly for helping him, after which he just wanted to sit and enjoy a quiet drink, chatting to other pub locals - Derek worked out how to afford more regular visits including taxi fares and drinking money. Like many older people who live in residential or nursing homes, he did not have control over his spending money, but through these visits, this gradually changed. Derek now knows how much money he has to spend, he looks after his

money, and he plans what he spends it on.

Derek had been married and divorced twice. He has three children, a son and daughter from his first marriage, and another daughter from his second marriage. His son visits him every couple of weeks or so, but he has not seen his younger daughter for 30 years. He last saw his older daughter a few years ago, when she visited him in hospital after his accident. He does not know where she lives now.

No one at the care home knew about Derek's marriages nor of his estranged daughters. After much discussion with his staff Derek decided that finding his daughters should be left to 'the experts' - in this case, the Salvation Army's.

Derek's life - then and now

Derek's life has changed with his regular visits to the pub where

he sees friends, occasional visits with his brother and the search for his daughters. He is more in control of his life, making decisions about arrangements and money and generally feeling very positive. The people in his life have expanded, from his son, brother and care staff to:

- The pub landlady.
- The barmaid.
- The regular taxi driver.
- Other drinkers at the pub.

It has also been quite a change for the care staff working with him. They know far more about Derek. They have also been challenged to think about the specific things an individual might want to do for which the more usual group response found in care homes (shared activities, communal meals etc) is not appropriate - and how to support someone to achieve more and more of this for themselves. The temptation

for staff to sort everything out was quite high. This may be a reflection on the way in which care home staff are used to describing their work as making sure that everything is done for you, so you don't have to worry. This approach, however kindly meant, may work to strip away any last vestiges of independence, and makes 'self directed support' less likely.

Being able to change and adapt your support is important. You can be in greater control of your service when you have control of your money, whether through self funding or through having an individual budget.

A framework for developing a support plan with older people

A crucial part of having an individual budget is deciding how to spend it to have the life that you want. The way to do this is by developing a support plan. This works whether your money is from an individual budget, or whether you are self funding and want to think about how to spend your own money.

A support plan helps people to think about how they want to spend their individual budget to help live the life they want. It has information that the local

authority needs to have to give them their money (individual budget).

Some people want help to develop their support plan. They can ask family and friends, or in some cases, an Independent Mental Capacity Act Advocate (IMCA) to help. There are other people who will help, for example care managers, social workers, people called person centred planning facilitators or advocates. Older people can also ask someone to do their plan with them if they choose.

The support plan belongs to the older person. Although developing a support plan does not always have to be linked to someone receiving an individual budget, anyone using an individual budget should always have a support plan.

A budget holder³ needs to see the support plan to check that it has all the information it needs, and will need to keep a copy of some of the information. A support plan should tell the budget holder what is important to the older person, what they want to change and what steps they are going to take to make these changes and how they plan to use their money to achieve this.

These questions are questions to help an older person, and their family or friends to think about their life. This is one approach to developing a support plan.

Question	Additional Prompt Questions
<p>How did you get where you are today?</p>	<p>Tell me about yourself? How are you today? Tell me what you are proud of, like family, work Who was in your life in the past?</p>
<p>Who is in your life now?</p>	
<p>What about where you live?</p>	<p>What time do you spend with others? What time do you spend on your own?</p>
<p>How do you spend your time?</p>	<p>What is a good day for you? What is a bad day for you?</p>
<p>What ideas do you have about how you would like your life to be?</p>	<p>Would you like to see and hear what other people have done or other examples of support plans? What matters to you? What is important to you? What do you miss that you do not do anymore? What would it take to get that back on track? How would you like your week to be? What do you want to change about your life? What do you want to keep the same?</p>

What are your ‘must haves’ and what are your ‘like to haves’?	
What is, or could get in the way?	How is your health? Is there anything that you need to leave or grieve for? What are you worried about?
What or who could help?	
What would life be like if all this went well?	Where do you want to be in 12 months time?
How are you going to use your money? What will you spend it on?	Provide information about the options (e.g. Direct Payment, indirect payment, care manager commissioning on your behalf, or an individual service fund) Do you know who to ask or where to go for advice?
How are you going to manage your money and your support/help?	Do you need any help in managing your money or managing your support? How do you want us to help you if there is a crisis? Do you want to have a contingency plan?
What are you going to do to make this happen?	

This document was developed with contributions from: Helen Sanderson, Carey Bamber, Helen Bowers, Pauline Doyle, Judith Whittam, and the Manchester, West Sussex, Bath and North East Somerset Individual Budget pilot sites.

Some people like to use big posters to capture their information, and we have developed one that people can put on the wall and fill in (see below). Some people want to develop support plans with other people who are doing the same thing. This can be done over two days and the process is called 'Planning Live'.

All of these ways work for different people. Some people write a few pages and stick a photo on the front. Older people are encouraged to choose what feels right for them. Their care manager should be able to help people to get the support they may need to do this properly.



Chris's story describes the difference that an individual budget can make

Chris's story

Mum, who is aged 80, has multiple physical and mental health issues including short term memory loss. Dad, who is 84, is registered blind and has physical and mental health issues including short term memory loss. They are a close couple that have been married for 60 years.

Although my father is the primary carer for my mother I provide significant and increasing support to them both. Social Services initially provided support through an agency. While this was OK, attendance to get Mum up in the morning varied between 9.00am and 12 noon, which they found difficult, as they were unable to plan things.

My mother was regularly booked into a residential care home to give dad much needed breaks. She hated being parted from my father, as with the exception of hospital stays, they had never been apart.

I heard about Individual Budgets and asked if my parents could be part of the Local Authority's pilot for older people. Following

acceptance on the pilot, we received a resource allocation based on Mum's existing package, and a small amount for my father to meet his increasing needs. I then developed a support plan with my parents and the rest of the family.

My parents decided that employing their own staff would be best. We wanted to pay good rates and Dad wanted time off from 'outsiders visiting'. We ended up agreeing that Mum's Personal Assistant (PA) would work more hours than agency workers previously had and that we could pay a decent rate if I provided support at the weekend. Instead of Mum going into residential care ("with all old people"), we arranged for my parents to visit a small hotel in Bournemouth, so they could have a break together. I arranged for a local agency to visit Mum at the hotel and to take her out in her wheelchair on a couple of afternoons. Friends took them down and brought them back in return for a good meal out. An additional grant was made available for equipment to reduce the risk of Mum falling.

These relatively small differences have made a huge difference to my parents and indeed for the whole family.

- Mum's PA now visits at a time that suits her.
- She has a bath everyday which she loves as it helps ease her painful joints. She also has help with ironing and other tasks. The agency staff commissioned by social services were only allowed to undertake personal care, which put extra pressure on my father.
- My mother's PA also takes her to the day centre instead of her having to wait for the bus, which came at different times and had to collect other people.
- The PA's hours accrue when they go away so they can be used flexibly and provide support when one of them is unwell. Mum has had no falls during the night since the equipment was installed six months ago. Previously she fell about once a week.
- My parents now enjoy regular breaks together and Dad has male company once a week to take him for a walk. He was used to exercise, but had lost his confidence following a bad fall. They go for a pint on the way home. His PA also helps do small DIY jobs that with the loss of his sight he is now unable to do.
- The reduced falls require less visits to A&E
- Now I have people around to help when things go wrong, which is great as I work full time.

- ¹ The six factors are: delivering services closer to home; early intervention and assessment to pick up support needs; management of long term conditions in the community; early supported discharge from hospital; access to hospital care when needed and quick access to specialist centres; partnerships with older people and their families.
- ² The work described in each chapter was undertaken by a facilitator working with Helen Sanderson Associates or the Older Peoples Programme.
- ³ The budget holder is the person who has the legal responsibility for allocating public money to people with support needs.
- ⁴ This analysis is taken from a background paper produced for the Independent Living Review on independent living and older people. It was discussed at a stakeholder workshop on 16 January 2007, and is included here because of the direct links between this work, and the development of self directed support and person centred support planning.