

# Key elements of personalised care planning in long term conditions and personal health budgets

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Written by Jo Harvey of Helen Sanderson Associates with the Department of Health's personal health budgets pilot programme



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## 1. Introduction

The personal health budget pilot programme team commissioned this project in early 2010 to explore best practice in care planning for long term conditions, and how this might help when developing care plans for personal health budgets.

Specifically, this project sought to identify common elements of care planning from a range of initiatives focusing on long term conditions, as well as identifying additional elements that might be required for personal health budgets.

The development of new approaches to personalised care planning is recognised as a crucial component in the implementation of effective personal health budgets. While there are many similarities between good care planning without a personal health budget, planning *with* a budget is different. If a person knows how much money is available to help address their health outcomes, this can empower them to be creative about best meeting their needs, while striking a balance between risk and potential benefits.

This work was facilitated by Jo Harvey of Helen Sanderson Associates, and began with a small workshop that included representatives from the Department of Health's personal health budgets delivery team and long term conditions team, the Year of Care National team, the Co-creating Health Initiative, Expert Patients Programme, Norfolk Coalition Of Disabled People and a personal budget user with extensive experience in social care support planning.

This is not a DH policy document or a prescriptive guide to personalised care planning, but it is intended to offer a summary of learning from long term conditions, with the aim to provide a useful framework to pilot sites when approaching the planning of personal health budgets.

## 2. Background

Current practice around care planning has evolved in a number of different areas, especially for people with long term conditions. These areas include:

- Personalised care planning for people with long term conditions
- Diabetes Year of Care
- Co-creating Health Initiative
- Personal health budgets

### 2.1 Personalised care planning for people with long term conditions

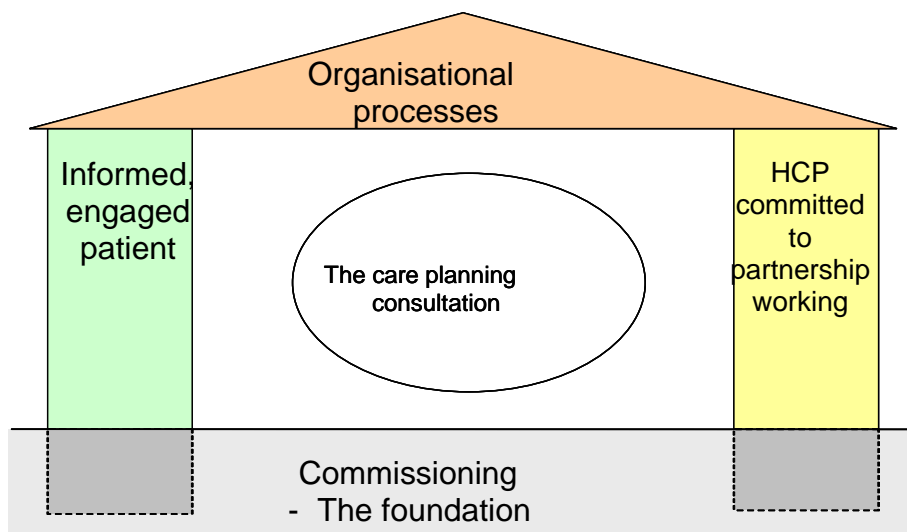
The keystone of any personalised care planning is a conversation between the person and the healthcare practitioner about the impact their condition has on their life, and how they can be supported to best meet their health and wellbeing needs in a whole-life way. The care plan is owned by the individual, and shared with others with their consent. It is important that a discussion takes place, there is a record of it, and people know they have a plan.

There is some variation in how this is delivered across the country.

### 2.2 Diabetes Year of Care

The Diabetes Year of Care is a partnership initiative between the Department of Health, Diabetes UK, The Health Foundation and NHS Diabetes.

The Year of Care approach puts people with long term conditions in the driving seat of their care and supports them to self manage. It does this by making routine consultations between clinicians and people with long term conditions truly collaborative through care planning and ensuring that the person is aware of their results prior to the consultation. It then ensures that the local services people need to support this are identified and made available through commissioning. To achieve the best outcomes, both effective care planning and commissioning have to be in place and working together.



## 2.3 Co-creating Health Initiative

The Co-creating Health Initiative is a three year demonstration programme, funded by the Health Foundation. It is designed to provide self-management support for people with long term conditions and to embed personalised care planning into health communities involving primary and secondary care. The programme has worked with clinical teams supporting people with diabetes, COPD, persistent pain and depression. Learning from the project has found that the following core components are essential to embedding self-management support and personalised care planning into the routine practice of busy clinicians and the wider NHS:

- Articulate an unambiguous high level description of the purpose of personalised care planning and ensure that this description is theoretically principled
- Ensure that there is available evidence to support that description
- Ensure that each domain of the high level description is measurable
- Ensure that clinical teams develop process measures that lead to improved outcomes
- Measure to improve
- Invest in staff development
- Make the right thing to do the easy thing to do
- Develop close links with local commissioners

## 2.4 Personal health budgets pilot programme

Personal health budgets are a means to give people more choice and control over the health care they receive, by making them aware of the money available to be spent on their care. Personal health budgets are currently being piloted by around half the PCTs in England. Sites are exploring how personalisation in health could work for a range of groups and conditions, including continuing healthcare, mental health, long term conditions and learning disabilities.

The West Midlands SHA has undertaken some work to build on the learning around personalisation in social care. This resulted in several key principles, including:

- Before they begin planning people need to know what should be in a care plan and the criteria by which it will be agreed. Frameworks and templates have been developed to give people this guidance. Also many planning tools have been developed with people and professionals to support the planning process. They include cards, graphic templates and workbooks.
- Any planning conversation needs to address what is important to, and for, people; what is working and not working; and what they hope to achieve.
- Those responsible for agreeing plans need to use the same criteria as set out in the advice to the people who are writing the plans.
- Best practice in planning and brokerage suggests that local authorities should develop a mixed economy of resources for help with support planning.
- Planning should be kept simple – not over-complicated
- There has to be a huge cultural shift and change in thinking about power within the workforce to support people really being in control.

### 3. Key elements of a good personalised care planning process

Following review of the learning from each of the projects the group identified the key elements of all good personalised care planning. These include:

- Agree the purpose of the plan, or any planning process/discussion at the outset
- Timely and relevant information available beforehand
- Description of clear goals and outcomes,
- Identification of how the person will 'self care'
- Detail about how will people meet their outcomes
- Contingency planning and risk management
- List of actions and who is responsible for each
- Record of who has been involved in the care planning
- How and when the plan will be reviewed.

In addition, for personal health budgets the care plan should record:

- How the budget is going to be spent
- How the budget is going to be managed.

This is not a prescriptive or exhaustive list but a broad framework of what we see as the essential components of any personalised care planning conversation discussion or consultation.

#### 3.1 Agree the purpose of the plan or planning process/discussion

Having a clearly defined purpose for what the care planning process is for is important. This should be tailored and proportionate to levels of need.

For example someone with diabetes who is otherwise fit and healthy, part of their annual review could be where they can discuss how they are managing their diabetes, how confident they feel in doing this, what their information needs are and review their outcomes/goals. This discussion and any actions agreed could be written into a formal plan or recorded in their notes.

Or

For a person with a multiple, complex long term condition (or a single dominant complex condition such as dementia) it is a process that will include the above but also involve coordination of services, a medication review/plan and contingency planning for exacerbations. This may involve a more detailed written care plan that will be used to coordinate all the support they will receive.

## 3.2 Timely and relevant information available beforehand

For a person to be able to fully engage in the care planning process and to make key decisions about managing of their condition, they need to be fully informed about their condition and other relevant information. This may include results, the personal health budget available to meet care needs, the care planning process and the options available to a person.

Learning from the Year of Care project has shown that fully engaged and informed people are a key component of a successful care planning process. In particular this project identified that sending out a person's annual review results (i.e. blood and urine tests, blood pressure, weight and foot and eye tests) before they attend for the care planning consultation has been hugely successful and well received both by people and healthcare practitioners.

Learning from support planning in social care has shown us that presenting people with information in a form and manner that makes the most sense to them is crucial if they are to fully engage in decision making within in the planning process. There are some person centred tools that can support this, e.g. Decision Making Profiles that ask the person how they like information presented to them, how they can be supported to understand that information and best and worst times to ask them to make decisions.

## 3.3 Clear goals or outcomes

There should be a clear link between the development of specific outcomes and goals to the assessed needs of the person. The care plan must set out how the services to be arranged should achieve these outcomes. Known as the 'golden thread' it has shown the vital importance of making these links to support creative and innovative use of personal budgets.

Being truly person centred is about recognising people within the full context of their lives and how they live them and not just focusing on their health condition. Outcomes will need to be based on what is important to people within these contexts and specifically relate to them as individuals.

James is 26 and two and half years ago had a C5/6 break of the spine. James, an active man before his accident, has worked hard to regain the use of his arms and build up his strength. When care planning with James he identified that it was really important to him to increase his stamina and fitness levels.

Through the planning conversation the focus was on what increasing his stamina and fitness levels would look like for him specifically. The following outcome was developed:

*"Being able to tolerate 12-14 hours per day in my wheelchair without being too tired and having to go to bed. – This would enable me to do more things during the day. At the moment I can only plan on doing one thing per day."*

### 3.4 Self care

A key aim around supporting people with a long-term condition is for people to gain confidence and skills to be more independent, in control of their condition and able to manage their conditions themselves. Skills for Care and Skills for Health have worked with people to develop the document “*Common core principles to support self care - a guide to support implementation*”. This defines self care in the following way:

*“Self care includes both self care and self management. Self care is about individuals taking responsibility for their own health and well-being. Self management is about individuals making the most of their lives by coping with difficulties and making the most of what they have. It includes managing or minimising the way conditions limit individuals lives as well as what they can do to feel happy and fulfilled to make the most of their lives despite the condition.”*

Supporting self care is about working in partnership and not about healthcare practitioners just handing over responsibility to individuals. Therefore the personalised care planning process needs to include as part of the conversation how the person can be supported to self care as part of managing their condition and achieving their outcomes.

James identified what he could do to help himself achieve his outcomes:

- Spending more time in my chair than I do now. This means getting up in time to do this; gradually increasing my tolerance of being in the chair; improving my sleep pattern by doing more during the day, avoiding afternoon naps and listening to music to help me get to sleep.

Using the rowing machine 3 times a week and the leg bike 5 times a week.

### 3.5 How will people meet their outcomes

A key part of the personalised care planning conversation is providing people with the opportunity to explore solutions to their agreed outcomes. These should make sense to them and fit with how they would choose to live their lives and manage their condition. Providing people with timely relevant information about local options, discussing self care and self management are all significant. However, the planning conversations must also include a discussion about the services a person may wish to use.

One of the critical success factors for personal health budgets will be achieving an optimum level of flexibility and room for innovation and creativity to unlock better solutions for individuals than the current system provides. Therefore the personalised care planning process must provide opportunities to discuss these creative solutions. The care plan then needs to record the services the person will be using.

James linked his outcomes and self care to the services he planned to use:

- Working with my physio to ensure my posture is correct in my new wheelchair and it is set up correctly for me.

Support from my personal assistant.

### **3.6 Contingency planning and risk management**

Part of the care planning conversation will need to focus on how changes to a person's condition could be managed. It may be if the person has a fluctuating condition with a clear history then plans can be discussed as part of the care planning process how these fluctuations can be managed and costed.

There will also need to be a discussion about the management of risk within the care planning process. Being overly risk averse can prevent people from achieving their goals. Creative and innovative solutions should be considered and discussed, for example the use of assistive technology to support independence.

Any discussion about risk should be realistic and aimed at enabling people to make the decisions that are right for them. This may require balancing potential risks and consequences with the benefits associated with any particular decision. There is a delicate balance between empowerment and safeguarding, choice and risk.

### **3.7 Actions**

At this stage of the process/conversation, the person and the healthcare practitioner should agree a set of action points, deciding who will be responsible for achieving each of the actions and deciding how and when the actions will be reviewed. Actions are more likely to be undertaken if they are detailed, specific and set out within a given timescale.

### **3.8 Recording who has been involved in the planning process**

This should record who has been part of the care planning process. This is particularly significant where person has complex health and social needs and there are a number of healthcare practitioners involved in supporting the person. In this case there will be one named lead coordinator who will be identified in the plan.

### **3.9 When and how the plan will be reviewed**

Reviewing should be flexible, proportionate and focused on reviewing outcomes. The proposed timescales for reviewing may be related to the purpose of the care planning process and the complexity of the person's situation i.e. for a person with high level complex long term conditions the reviewing of the care plan may need to be more frequent than for a person with low level needs who may only have a review once a year.

The care plan should record how this review will take place, what will be reviewed (e.g. whether needs are being met and change in need and financial review) and how often.

## 4. Additional elements required for personal health budgets

There will be some additional elements required for people receiving personal health budgets.

### 4.1 How the budget is going to be spent

Pilot sites will need to explore how they set the budget and be able to offer people an indication of the resources available before they begin the care planning process.

The care plan will also need to have a clear record of how the personal health budget is going to be used. This should include:

- The amount of the personal health budget
- Clear costs for support either through employing personal assistants or services or through organisations or agencies
- If a person employs their own personal assistants they will need to include costs related to insurance, training and expenses
- One off purchases for equipment, tele-healthcare or technology
- Contingency costs.

### 4.2 How the budget is going to be managed

As part of the care planning process the healthcare practitioner will have to discuss with the person how they wish their personal health budget to be managed. There are currently three options proposed for managing personal health budgets that are being tested through the pilots (or a combination of all three);

- Notional budget – where an individual understands the amount of funding available to them and decides how the budget is used. The primary care trust still commissions services, manages contracts etc. Notional budgets could be an option for individuals who want more choice and control over their healthcare but who do not feel able or willing to manage a budget.
- Real budget managed by a third party – where the individual knows how much funding is available to them but a third party holds the funding. This maybe a budget-holding lead professional, a GP practice, a provider organisation, an NHS Trust or an organisation like a community interest company.
- Direct healthcare payment – where the individual receives the funding that is available to them as a direct payment for them to manage themselves. This is only available to authorised pilot sites.

More information on specific requirements around direct payments will be available from the guidance documentation currently being written by the Department of Health.

We expect people to use personal health budgets to purchase a range of services, from traditionally commissioned services to more personalised and individualised options. Different options will give people different levels of choice and control.

## **5. Further information – what’s already out there to help?**

Whilst exploring the best practice and learning from the different initiatives already described, it was clear that there were also issues that whilst not forming a clear part of the care planning process, will have a significant impact on the successful implementation of personalised care planning for people who have a long term condition and a personal health budget. This is not an exhaustive list but will hopefully prove useful information to pilot sites.

### **5.1 Informed patients**

#### **5.1.1 Diabetes Year of Care**

The Year of Care pilot project successfully piloted the sharing of the person’s annual review results, prior to the care planning consultation. The test results were sent out in a letter one week before the consultation with prompts in the letter for the person to consider before the consultation.

#### **5.1.2 Expert Patient Programme**

The Expert Patients Programme (EPP) is a peer led self-management programme specifically for people living with long-term conditions. The aim of the programme is to support people in increasing their confidence, improving their quality of life and better managing their condition.

Course places are free to individuals and there is a commitment to increase the number of EPP course places to 100,000 by 2012. Expert Patient Programme Community Interest Company was established in 2007 to facilitate the delivery of courses across the country.

#### **5.1.3 Information prescriptions**

Information prescriptions guide people to relevant and reliable sources of information to allow them to feel more in control and better able to manage their condition and maintain their independence. They are offered to everyone with a long term condition in consultation with a health or social care practitioner. They are nationally recognised as a source of key information on services and care that can be integrated into the care planning process.

#### **5.1.4 NHS Choices**

NHS Choices is an online information source that provides patients with access to comprehensive, easy to use information about conditions, treatment, advice about healthy living and comparative hospital data. It uses state-of-the-art interactive and multimedia technology and is designed to help people make the most of their own health.

## 5.2 Workforce development

There are a number of pieces of work that could already support workforce development.

NHS East of England has developed an interactive workforce guide *Understanding Personal Health Planning: A Workforce Guide to Support People with Long Term Condition*, which can be found at [http://www.eoe.nhs.uk/personal\\_health\\_planning/](http://www.eoe.nhs.uk/personal_health_planning/)

This interactive guide consists of the following elements:

### The PHP journey

Essentially this journey describes the three key stages of supporting an individual with LTCs through the process of PHP; the preparation of supporting an individual to understand what PHP may mean for them. Supporting individuals to create a Personal Health Plan document and enabling individuals to live with PHP through the realisation of their personal goals.

### PHP competencies

Through regional engagement events and from shadowing interactions between key workers and individuals six core competencies were developed which articulate the knowledge, skills and behaviours required to support an individual through the PHP Journey. Two of the core competencies are specifically for managers of key workers and four are for key workers themselves. These were mapped to the common core principles for self care, Knowledge and Skills Framework, 4 pillars of self care and Information Prescriptions KSF levels.

West Midlands SHA has developed a workforce planning tool as part of their personal health budgets pilot project. This tool can be found by following this link to the Department of Health's personal health budgets Learning Network website and downloading the workforce tool.

<http://www.dhcarenetworks.org.uk/PHBLN/Topics/latest/Resource/?cid=6943>

NHS Employers have recently launched a personalised care planning e-learning tool, which is available to NHS and social care staff and can be accessed via the NHS Employers website: [www.nhsemployers.org](http://www.nhsemployers.org)

Supporting Self Care has developed three 20 minute e-learning modules for health and social care professionals which aim to raise awareness of the self care support available and the benefits of supporting people with LTCs to self care.

<http://www.e-lfh.org.uk/projects/supportingselfcare/index.html>

The Social Partnership Forum, the Department of Health and NHS Employers have recently published *Personal health budgets: understanding the implications for staff* which is available from

<http://www.dhcarenetworks.org.uk/PHBLN/Topics/latest/Resource/?cid=7346>

## 5.3 IT Infrastructures

### Yorkshire and Humber integrated IT system (System 1)

The IT solution also supports approaches for both personalised care planning and the Year of Care and captures key information about joint goal-setting and action planning agreed between a person with diabetes and their clinician.

## 5.4 Commissioning and market development

Guidance for commissioners published in January 2009 which explains what personalised care planning is, how it can benefit patients, staff and commissioners and how to commission it as part of a care pathway or core service:

*Supporting people with long term conditions: commissioning personalised care planning: – a guide for commissioners.*

[http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\\_093354](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_093354)

*Working together for change*

<http://www.dhcarenetworks.org.uk/Personalisation/Topics/Browse/General/?parent=2734&child=5802>

## References

*Understanding personal health planning: a workforce guide to support people with long Term conditions*

[http://www.eoe.nhs.uk/personal\\_health\\_planning/](http://www.eoe.nhs.uk/personal_health_planning/)

*West Midlands SHA workforce planning tool*

[http://ifh2.westmidlands.nhs.uk/ifh-key-documents/cat\\_view/12-investing-for-health-key-projects/96-personal-health-budgets/125-personal-health-budgets-toolkit.html](http://ifh2.westmidlands.nhs.uk/ifh-key-documents/cat_view/12-investing-for-health-key-projects/96-personal-health-budgets/125-personal-health-budgets-toolkit.html)

*Personal health budgets: understanding the implications for health*

<http://www.dhcarenetworks.org.uk/PHBLN/Topics/latest/Resource/?cid=7346>

*Supporting people with long term conditions: commissioning personalised care planning: a guide for commissioners*

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