



# **Personalised care and support planning handbook:**

**The journey to person-centred care**

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**Supplementary information on practical delivery**

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## Part 5: How to deliver personalised care and support planning



*Learning self-management was a revelation to me. It taught me to recognise the triggers and early warning signs that might precede an episode of illness, and what action to take in order to stop it in its tracks. I am now able to work, maintain and enjoy a healthy marriage with my wife and be a good father to my three children. My only regret about self-management is that I didn't discover it earlier.*

A person who uses mental health services

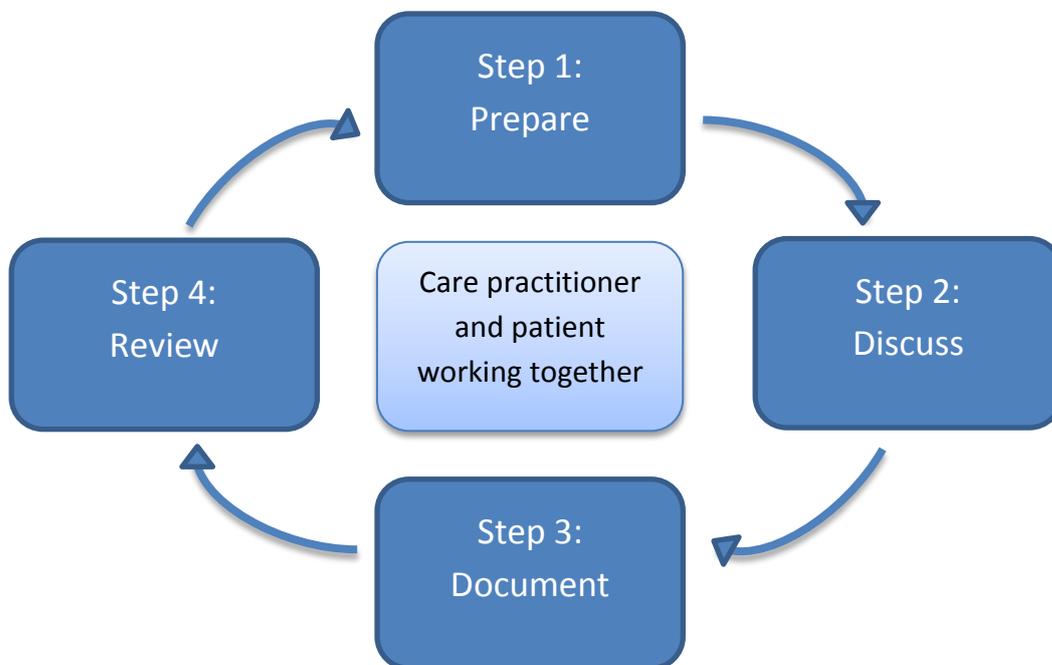


*Before, many patients with COPD were feeling hopeless, depressed and frustrated. A few months later they return in control of their illness and empowered to manage their lives.*

A doctor from Cambridge

### 5.0. Introduction

This section looks at the practical steps and the processes for delivering personalised care and support planning. The section follows the four steps identified in the [National Voices Guide to Care and support planning](#): prepare, discuss, document and review, however, all of these processes need to be considered together rather than in a linear sequence, and from the perspective of all those professionals, patients and carers who will have a role to play.



This guidance is not intended to be prescriptive but to stimulate thinking, and to share some suggestions and examples of approaches. Services are encouraged to design, test and implement models that will work for their own local needs.

This section looks at some of the practical steps that need to be taken to deliver personalised care and support planning, and considers these against the framework of the House of Care (see [Part 1](#)) i.e.:

- patients and carers are supported to be active and engaged in discussions about their care and support
- professionals being committed to working in partnership with patients and carers, and also with other professionals across health and social care
- systems being in place to organise resources effectively
- having a whole-system approach to commissioning health and care services

### 5.0.1. Key design decisions for personalised care and support planning

Prior to introducing personalised care and support planning within a service, there are some key considerations and decisions that need to be made when designing your approach. Some of these decisions will be needed at the commissioning level but then need to be translated into plans at provider level:

1. **Which patients will be offered a personalised care and support planning discussion?**
2. **Where will discussions take place?** For the majority of patients this will be within the service setting, but for others it could be in their home, or in their care home. This may depend on who is leading the care planning discussion.
3. **What extra steps are needed for people with complex cases?** What other systems and processes need to be in place to help provide the best care for people with complex needs or where difficult decisions need to be made? [See the handbook on [multidisciplinary team development](#)]
4. **What infrastructure needs to be in place?** What systems and processes will be used to help deliver personalised care and support planning?
5. **Who will take the lead for personalised care and support planning discussions?** There are a number of different roles that could take responsibility for leading the discussion, clinical and non-clinical. Consideration should be given to the needs of the patient, the skills of the professional, and continuity of care. Decisions should also be made about whether more than one lead is required, for example where one person will help facilitate the conversation, but another person would take responsibility for ensuring care is being delivered in accordance with the plan.
6. **Who needs to be present during discussions?** People might wish to have their carer, family member, friend, supporter or advocate with them and this will be particularly important if those people play a significant role in their care, or if there are any issues in terms of communication, health literacy, or capacity for decision-making. There might also be other health or social care professionals that should be involved in the care and support planning discussion.

## 5.1. Step 1: Prepare

Preparation is key to ensuring the care and support planning discussion pulls in the right information.

The care and support planning discussion should be separate from any assessments to allow time for reflection, gathering and digesting information, and to consider who needs to be involved. It will be important to consider how discussions will be scheduled, the length of consultations that will be required and make any alterations to the booking system

### 5.1.1. Identifying and contacting patients and carers

As covered in [Part 4](#), there are various methods and tools for identifying which patients to prioritise for personalised care and support planning. Once decisions have been made at a strategic level about which patients would benefit most from personalised care and support planning, there will be some administrative tasks in identifying individuals on the clinical system and setting up a way of tracking whether patients have had a personalised care and support planning discussion.

Patients and carers need to be contacted and given information about the care and support planning process in a way that they can understand. There need to be systems for inviting people to attend appointments. You might develop invitation letters, make contact via phone, or discuss during a routine appointment. People will need to understand why the offer is being made to them, what to expect, and how they can prepare. They will also need to know that they do not have to agree to be involved.

### 5.1.2. Helping individuals to prepare

Personalised care and support planning relies on a partnership approach but will often be initiated by health and care services. Services need to be clear on how they will structure these discussions and how they can support people to prepare.

Patients may need time and some prompts to help them prepare for a discussion on care and support planning. They may wish to have time to discuss their feelings and ideas with carers, family, friends or with people who have been through similar experiences.

They may also want to know some key information about their health, such as test results, or have access to good quality information about options for treatment that they can consider in advance.



There are a number of resources available which might help people to prepare:

- The [RCGP resource on care planning](#) includes a number of sample letters and prompts
- Macmillan Cancer Support's booklet on '[Assessment and Care Planning for People with Cancer](#)'
- The National End of Life Care Programme developed '[Preferred Priorities for Care](#)' – a resource to help people think through and write down their preferences and priorities for end of life care



### **Case study: Year of Care – Preparing for discussions**

The Year of Care programme demonstrates how routinely introducing a preparation step prior to the care and support planning conversation enables the person to be better prepared, to take a more active part and to make much better use of the information that is shared.

Following an explanation of the new process people with one or more LTCs receiving care in general practice are invited to come in for routine checks and tests with a health care assistant, who explains that the results of these will be sent to them in 1-2 weeks. These come with a simple explanation and some prompts to jot down questions, any areas of concern and think about what is important to them, in discussion with family and friends if they choose. They are then prepared for the second care and support planning visit and conversation which allows time to share information and thoughts, look forward to what would help them have a great life over the next few weeks, month or a year and focus on their goals and action plans.

This new way of working is better for everyone.

The following diagram shows the process for the care and support planning discussion, starting with the preparation.



From Kings Fund (2014) *Delivering better services for people with long-term conditions: Building the house of care*

Some key considerations in helping patients and carers prepare might include:

- **What information do people need about their health and care that will help them in making decisions and thinking through outcomes that they want to achieve?** For example:
  - Test results explained in an understandable manner
  - Access to their clinical record, either online or in paper format
  - Information leaflets, videos, audio or websites to help people understand more about their condition and treatment options
  - [Patient decision aids](#) to help people consider which treatment options will work best for them
- **What support is available to people who may need assistance in understanding or interpreting information, making choices, or thinking through what is important to them?** Will your methods of communication work for all patients and carers? People with lower levels of confidence, health literacy, activation, or people with communication or access needs, might require some additional support to help them prepare for personalised care and support planning. Peer support schemes with patient groups, volunteers, health champions, voluntary and community services, or health trainers.
- **Is there any information you would like to collect from patients and carers prior to the care planning discussion?** For example, surveys measuring quality of life, levels of patient activation, functional assessments. How will you collect this information? And how will it be used? This information can be used to inform the care planning discussion by better understanding the knowledge, skills and confidence that the individual has, and what is important to them. It can help the care practitioner adapt the conversation, and can also provide a benchmark to help measure whether the process of personalised care planning impacts on outcomes.

### 5.1.3. Practitioner preparation - the “professional’s story”

Care practitioners also need to prepare for the care and support planning conversation, both in terms of having the right attitude, skills and approach to facilitating the discussion, and also in being able to represent clinical and professional assessments of need.

The care practitioner can prepare by gathering relevant information about the individual’s health and care needs. This may require gathering information from other professionals or services to ensure they can represent an accurate picture of the individual’s current situation, and possible options for care and support that can be explored.

Some key considerations in building the ‘professional’s story’ are:

- **Can you identify which professionals are involved in the individuals’ care?**
- **How is information being shared between these different professionals/services?**
- **Do other professionals need to be part of the care and support planning discussion?** In more complex cases, it might be appropriate for specialists or other professionals, such as social workers, to be involved or lead the discussion.

## 5.2. Step 2: Discuss

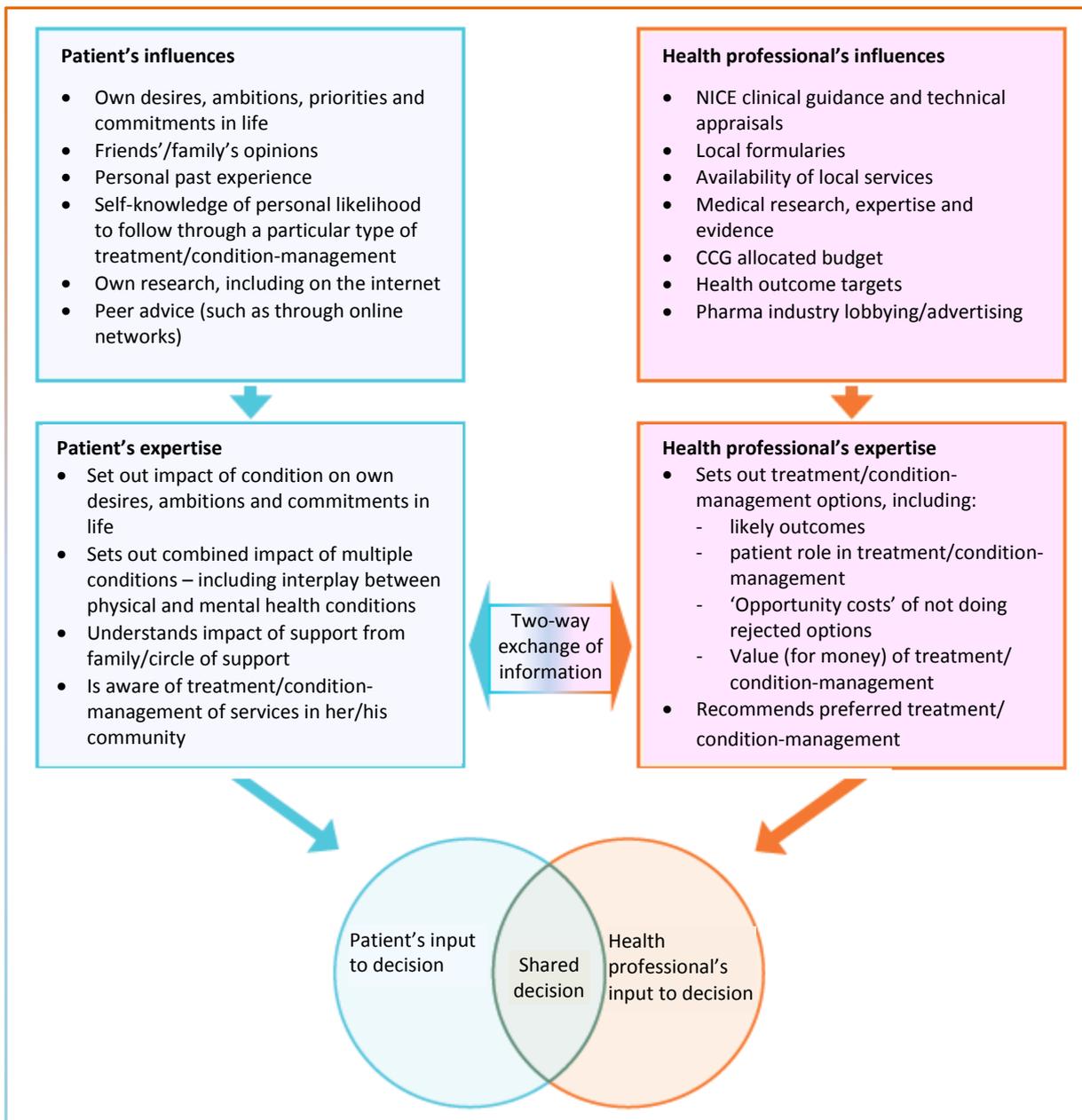
This step is the main focus of the personalised care and support planning process and focuses on the relationship and dialogue between the individual, carer and care practitioner.

### 5.2.1. Taking a partnership approach

Care practitioners need to be prepared for a different relationship whereby they can recognise the knowledge, skills and assets that patients and carers have. They need to work in partnership, listening to what is important to the individual – their preferences, hopes and concerns, and their own ideas for what might work. The conversation should encourage reflection, shared decision making, open questions and sometimes negotiation.

The report *When doctors and patients talk: making sense of the consultation* (Health Foundation, 2013<sup>1</sup>) explains some of the anxieties that both patients and clinicians can have, and the importance of helping patients to understand how consultations are structured. Some patients and carers may lack confidence or have lower levels of health literacy or activation and may need more support to participate in the discussion. Care practitioners need to consider how they might tailor their approach to suit the different levels of knowledge, skills and confidence that people have.

*Figure 1 A model of how the influences, expertise and roles of health professionals and patients should inform shared decision-making<sup>2</sup>*



### 5.2.2. A flexible framework for the discussion

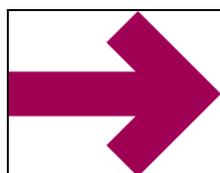
As outlined in the principles developed by National Voices (see [section 2.3](#)), the discussion should start from the perspective of the individual, building on their reflection during the preparation stage. The perspective of carers and family members are also important as care and support arrangements might be reliant on their involvement, or have an impact on their lives.

Care practitioners may need to use open questions and listening skills to help encourage patients and carers to feel comfortable sharing their views. Starting with broad questions such as “*What is important to you?*”, “*What does a good day look like?*” or “*What do you hope for?*” may help to set the tone for the discussion. More advanced skills such as

motivational interviewing, coaching and 'solution focussed' approaches may be required to help facilitate the discussion.

The conversation should move through a systematic process of sharing information, discussing options, setting goals and developing an action plan. Not all of the discussion will be recorded but having a framework for the discussion will help ensure everything is included. However, whilst it can be helpful to consider particular questions to ask, or categories to discuss, the conversation should not be rigid and should not feel like a tick box exercise.

The conversation should also be flexible to adapt to the different levels of knowledge, skills and confidence the individual has. This will also influence the goals and actions that are discussed.



The Gold Standards Framework Centre in End of Life Care developed an [aide memoir](#) for conducting holistic assessments of supportive and palliative care needs for adults with cancer. They used the acronym PEPSI COLA: physical emotional, personal, social support, information and communication, control and autonomy, out of hours, living with your illness, and after care.

### 5.2.3. Addressing individual needs

By considering the specific needs of individuals, personalised care and support planning looks at health and care amongst the wider context of a person's life. There may be a number of sensitive issues which impact on an individual's perceptions about their physical and mental health and the care and support they need, as well as the level of support they need to be an equal partner in discussions.

There may be personal issues and significant life events relating to lifestyle, relationships, employment or finances which, though not specifically related to health and care, can have a significant impact on health and wellbeing both for the individual and for their carers and support network. Likewise, living with a long term condition, can impact on all aspects of a person's life, from how they cope in schools, where they live, the kind of employment they can seek, how they care for others, and what social activities they can join. Whilst the personalised care and support planning process may not be able to address these issues, they need to be considered in line with the health and care needs, goals and actions. Could they impact on the person's ability to achieve their goals? Does the individual have sufficient support around them or would they benefit from being connected to local support groups? Different strategies may be needed for different aspects of the person's life.

Personalised care and support planning can embrace diversity and help to address health inequalities by considering the specific needs of individuals and how these are currently being addressed by health and care services. It is important that no assumptions are made and that patients and carers feel they can be open and honest about their concerns and preferences. By co-designing care and support plans, this can help to ensure that goals and actions are appropriate and achievable for the individual's circumstances, aligning with their cultural and religious needs and their family and social networks.

A key part of the personalised care and support planning discussion is establishing what support the individual needs in order to break down any barriers and to help build their knowledge, skills and confidence, also known as their “activation”.

The Patient Activation Measure discussed in [section 4.5.1](#) provides a way of assessing how individuals feel about managing their health and care. This can provide helpful information for the care practitioner in understanding how they should approach the care and support planning discussion. The table below provides some examples of how care practitioners might tailor their approaches to patients with different levels of activation.

Activation level	Examples of tailoring support
Level 1	Focus on building self-awareness and understanding behaviour patterns, and begin to build confidence through small steps.
Level 2	Help patients to continue taking small steps, such as adding a new fruit or vegetable to their diet each week or reducing their portion sizes at two meals a day. Help them build up their basic knowledge.
Level 3	Work with patients to adopt new behaviours and to develop some level of condition-specific knowledge and skills. Support the initiation of new ‘full’ behaviours (those that are more than just small changes – e.g. 30 minutes of exercise three times a week) and work on the development of problem-solving skills.
Level 4	Focus on preventing a relapse and handling new or challenging situations as they arise. Problem solving and planning for difficult situations to help patients maintain their behaviours.

A greater understanding of an individual’s holistic needs will allow practitioners to match individuals with support and services that support them in managing their health and wellbeing. It may be helpful to involve additional support such as link workers, community navigators, advocates or translators to help individuals in contributing to the discussion and the shared decision making process, understanding the implications of different options, exploring the individual’s needs and identifying creative ways of meeting them.

The care and support plan may have unusual aspects; the question to explore is whether it will meet the assessed needs and lead to the desired outcomes. Care practitioners need to look beyond evidence-based care pathways to explore new, emerging models of care and support.

Some key considerations for addressing individual needs:

- **How can you establish whether there are issues of health inequalities, health literacy, or patient activation for your patients?**
- **How will you support and/or motivate people with lower levels of activation or health literacy?**

### 5.2.5. Goal setting and action planning

Individual goals need to feel important and relevant to the person. Goals should be based on needs, rather than services and should link to the outcomes that they want to achieve. Care practitioners should encourage individuals to consider specific, realistic, tangible actions that are needed to achieve these goals, whether these are actions for the individual and their family and carers, or actions that care practitioners need to lead. For example:

Instead of:	The plan should read:
<p><b>Need:</b> Fall prevention  <b>Goal:</b> Prevent A&amp;E attendances  <b>Action:</b> Attend physiotherapy appointments once per month</p>	<p><b>Need:</b> I need to build up my muscle strength to assist with balance  <b>Goal:</b> To be able to use the stairs without needing any assistance  <b>Actions:</b> Dr to refer me to a physiotherapist; I will discuss strengthening exercises with my physio; I will join a weekly walking group</p>

Goals and actions should not be limited to medication and treatment options. Personal goals might relate to family relationships, social support, diet and lifestyle, employment or education. All of these factors can impact on people's health and wellbeing.

Action planning may feel uncomfortable to a clinician where the patient is not willing to agree to something which the clinician sees as important or where clinicians are performance managed to deliver e.g. taking statins. Engaging with the process of personalised care and support planning is essential to find out what the patient is prepared to do in terms of their own care<sup>3</sup>. Likewise, the patient may have views which the clinician does not support. The discussion should work through the options available, discuss any differences in opinion, and agree joint priorities for action. It will draw together the person's own solutions, which they are committed and motivated to do, with the health professional's expertise about what might have proved useful for others and what research evidence suggests.

The action planning section of the care plan must specify clearly who will do what and when. Where individuals are taking responsibility for their own actions, it is helpful to discuss their level of confidence in achieving their aims using a scale of 1-10. They should not feel that they are taking on more responsibility that they are comfortable with. If their confidence is low, discuss whether the action is right for them, or how their confidence could be increased. It might be more appropriate to look at smaller tasks or changes; people are more likely to succeed if they have a higher level of confidence. Failure to deliver actions may further demotivate people. Try to focus on actions that score a 6 or higher.

Carers can play a significant role in action planning as they may need to take responsibility for some of those actions, or be able to support the individual to take responsibility. It is important that they are involved in the discussion and that they are comfortable with the detail.

Some key considerations for goal setting and action planning:

- **How will you ensure actions are being followed?** Where care services are responsible for particular actions within the individual's personalised care and support plan, how will you monitor whether they are delivering against these actions? By taking the lead for an individual's care and support planning, this does not mean taking responsibility for delivering all of their care and support, but instead taking responsibility for removing blockages where possible.
- **How can you support people who are lacking in motivation or confidence to take responsibility for some of their own actions?** Some people may feel reluctant or unwilling to take on tasks to help improve their health and wellbeing. It's important to explore the reasons for this. They may need some additional support to explore their feelings, or build their knowledge, skills and confidence. Think about what services are available to support them, for example health trainers, peer support, coaching or advocacy services.
- **What tools might help people to track whether they are achieving their goals?** It can be helpful and motivating for people to keep a record of the actions they are taking and whether they feel they are achieving their goals. This might mean keeping a diary, having a checklist, or charting changes, such as weight, blood pressure or mood. There are number of [health apps](#), websites and systems which patients and carers can use to help manage their health and wellbeing. Paper-based versions can work well too. Think about how you will encourage people to track their progress.

#### Case study: online self-management tools



Terrence Higgins Trust developed [myHIV](#), an online resource aimed at the groups most affected by HIV in the UK – African people, gay men and young people to help increase people's ability to manage their own HIV.

The interactive website offers information, advice, case studies, peer support via forums, self-management tools such as medication and appointment reminders, a tracker to record the severity of the virus and medication taken, as well as space for personal notes.

THT felt it was important to support individuals in recording their own health information as they have found people with HIV often dropped out of specialist healthcare services. Patients can find it difficult to have an open discussion about sexual behaviour with a clinician or might find it difficult to understand what the clinician is saying.

The online information is tailored to each targeted group, with culturally sensitive content and imagery. The information mirrors that offered during face-to-face consultations by THT's health trainers, who are based at NHS HIV clinics around the UK. The website is designed to encourage users to be open about their condition. These same trainers are also available to give email or phone advice via the website within 48 hours.

There are now over 10,000 registered users on myHIV. Three quarters of people using the site report an improved knowledge of HIV. Six out of 10 report being more confident when asking their clinicians questions and nearly seven out of 10 report an improved lifestyle<sup>4</sup>.

### 5.2.6. Exploring options and offering choice

Sometimes there may only be a small number of options available to address a person's needs, but where possible, people should not feel like they are restricted to selecting from a short 'menu'; they should be encouraged to think creatively about solutions which work for them. They may need some support to do this, or to have information about what is possible. This is where services provided by the voluntary and community sector such as peer support groups, advocacy and advice services, and information services can prove very beneficial.

Care practitioners also need to be aware of what the possible options are and how services can be accessed. There may be specific referral processes that they need to follow, or self-referral might be possible.

Options might include: traditional health and social care services; community based services; structured education programmes; the use of assistive technology i.e. telecare and telehealth; peer support (online or face to face); diet or exercise programmes; lifestyle change support services and palliative care. There might also be a range of 'more than medicine'<sup>5</sup> options within the local community which address their wider wellbeing such as volunteering, befriending, employment and welfare advice, arts classes, and many more.

It may be appropriate to offer the option of a [personal health budget](#) to the individual and their carer. Personal budgets have become widely available in social care and are being gradually rolled out across England in health. They give people more control over how their health needs are met which might include commissioning a service on an individual basis. Personal health budgets can be extremely beneficial for people who feel that traditionally commissioned services are not meeting their needs, giving people more choice and flexibility over how money is spent on meeting their health, care and wellbeing needs.



Listen to [Nikki](#) talking about how having a personal health budget has helped her to shape care around her needs.

Some key considerations in supporting choice:

- **What information do you have about possible options for care and support?** E.g. repositories of information or directories of services
- **Are there services in place to help people in understanding and making choices about their care and support?** Voluntary and community services can provide support to individuals in understanding and accessing support in their local community, such as social prescribing schemes, advocacy and advice services, or peer support groups.
- **Are there services available to support carers?**
- **Are you able to offer a personal health budget?** People in receipt of NHS Continuing Healthcare have a right to have a personal health budget, and from April 2015, there should be an option for others with a long-term condition who might benefit from a personal health budget.
- **What are the referral processes for these services in your area?**



*Peer to peer input fosters confidence. We often talk about cultural change in the NHS and how the way people think and behave needs to adapt to realise the vision we all share for improved outcomes for people. The same needs to happen for people and families if they are going to embrace the opportunity to take more control over their health and wellbeing. They need to believe that change can happen. The most powerful way to communicate new possibilities is for peers to talk to each other.*

*There is an innate trust between people and families with shared experiences. A robust strategy for the dissemination of accurate and useful information is vital, along with developing a regular feedback loop. This can be done in a number of ways, but one of the most robust is to involve people at every stage of development by creating a peer network.*

Jo Fitzgerald, Peoplehub peer network for personal health budgets

### **5.2.7. Planning for the future and contingency planning**

An important part of the personalised care and support planning conversation is about planning for the future and considering what needs to happen if there is any deterioration in health. This can include a number of different elements:

- Identifying triggers or early warnings so they can consider things to avoid, and strategies to put in place
- Identifying jointly prepared crisis plans, particularly for mental health. This might include plans for medication and treatments, self-care strategies, people to involve or not involve, and ways to access emergency support
- Identifying which services to involve and when i.e. when to use urgent and emergency care
- Recording preferences for end of life care and support, including where and how they would like to be cared for
- Recording views and preferences about their care if there is a loss of mental capacity. This is known as advance care planning and may include advance decisions to refuse treatment, e.g. 'do not attempt cardiopulmonary resuscitation' decisions
- Preparing for transitions e.g. young people moving into adulthood, or people with learning disabilities moving into independent living.

These types of conversation are particularly important for people with fluctuating conditions, high risk conditions or terminal diagnoses.

There are many considerations for these kinds of conversation and they must be handled with the upmost sensitivity. The conversation should be framed in a way as to normalise conversations about proactive planning for deterioration or death. It is not about scaring the person, but about having all the right information.

It is important to recognise that people can have different views on planning for the future, and that their preferences now could change as their situation changes. Some of their choices may impact on their loved ones and carers, and may even go against their wishes. The individual should be encouraged to have open conversations with their families.

Further guidance on caring for people approaching the last days to hours of their lives can be found at '[Priorities or care for the dying person: duties and responsibilities of health and care staff – with prompts for practice](#)'.

### **5.2.8. Discussing, managing and enabling risk**

Effective care planning needs to include a discussion about possible risks that might be incurred by following different treatment paths (including the choice to take no action) or using different services and support, and how those risks can be minimised to an acceptable level. Decisions will take into account the outcomes the person is seeking and bear in mind their particular circumstances, lifestyle and beliefs. If someone is feeling particularly unwell, vulnerable or scared, they may not want to take on extra risks and responsibilities and may prefer their care professional to advise on what they feel is best.

Risks also have an impact on families and carers and it is therefore important to consider their perceptions and feelings as part of the discussion.

Care professionals may have their own concerns about the levels of risk involved with different decisions, particularly when agreeing to more innovative models of care and support, for example when discussing plans to use personal health budgets. To support this, a risk-enablement process can be very useful, so that no single professional feels they must make all the decisions alone. These processes allow care professionals, patients and carers to call together a group of people familiar with health risk enablement to consider a particular risk. The group agrees how the risk will be managed and records that learning. Over time, a log of risk-enablement strategies accumulates that can be both a helpful local resource and a source of national good practice<sup>6</sup>.

### **5.2.9. Consent and information governance**

At the outset of the care and support planning discussion, it is important to establish consent with the patient and carer. The individual needs to properly understand the service offer, what can be achieved through personalised care and support planning, and how their information will be processed and shared with others. Where a carer/family member has lasting power of attorney, they need to provide consent on behalf of the patient for information to be recorded and shared.

Individuals have the right to refuse the offer of a personalised care and support planning discussion. They might feel their needs are already being met, or they may not feel ready to discuss broader aspects of their health and wellbeing. They may be reluctant to attend an additional appointment. In which case, they need to understand that their care will continue as it currently stands. A personalised approach can still be used but if patients are unwilling to attend a specific care planning appointment, it may be difficult to address their holistic needs, goals and actions in sufficient detail within a standard appointment slot.

In terms of sharing information, there should be a discussion about who would have access to the care and support plan. This could include care professionals who are part of the multidisciplinary team across health and social care. It also includes sharing information with family members and carers. The individual and their carer have a right to determine who has access to their information and should understand the implications of this. They might choose to proceed with care and support planning but limit who has access to their plan.

Consent can be recorded in a number of ways, verbally or in writing, as part of the care and support plan, or in addition to it. Services can choose their own models for consent but must ensure that patients and carers are fully informed, and that processes comply with NHS Codes of Practice and legal obligations for confidentiality, information security management, and NHS records management. For further information on information governance, please see the Health & Social Care Information Centre [website](#).

### **5.2.10. Care planning for those who lack capacity**

Duties to empower people to make decisions and take control of their care and treatment are underpinned by the Human Rights Act 1998, the Equality Act 2010 and the Mental Capacity Act 2005. However, duties to safeguard patients are also required by professional regulators and service regulators, and are supported in law. The Mental Capacity Act 2005 states that any decision made on behalf of a person who lacks capacity to make their own decisions must be done in their best interests and should be the least restrictive of their basic rights and freedoms. Likewise, just because an individual wishes to make what might be seen as an unwise decision, they should not be treated as lacking capacity to make that decision or be restricted from doing so.

Considerations around mental capacity should not bias care planning discussions to mental health needs only; physical health needs also need to be included.

Where a person lacks capacity and cannot consent to the involvement of others, the care provider must always act in the best interests of the person requiring care and support.

Some key considerations in managing consent and capacity:

- **How will you ensure that individuals have given consent?** How will you include discussions about consent as part of the care and support planning conversation? How will consent be recorded?
- **What training have staff had on the Mental Capacity Act and Best Interest decisions?** Staff (and volunteers) involved in care planning may require specific training in relation to consent and capacity. Alternatively, the service might only allocate trained practitioners to complex cases with issues relating to mental capacity.
- **Has a Lasting Power of Attorney for Health and Welfare been appointed?** If so they need be involved in the personalised care and support planning discussion and in decision-making
- **How can people who know the person best (carers, family friends) be involved in care planning?** Would an Independent Mental Capacity Advocate (IMCA) be appropriate for those who lack capacity and do not have family?

### 5.3. Step 3: Document

It is important to document the care and support planning discussion to capture all the key points. This constitutes the individual's 'personalised care and support plan'.

Plans should be proportionate to the needs to be met, reflecting the person's wishes and aspirations. So where someone feels happy that they are managing their condition well, the care planning discussion and the written care plan may be fairly short, provided both parties agree. Alternatively, for someone with fluctuating or complex needs, they may need to consider a number of different scenarios and plans for each of these.

#### 5.3.1. Presentation of the care and support plan

It is important that the individual and/or carer have a copy of the personalised care and support plan so that they can take ownership of it. The information in the plan must be meaningful, relevant and accessible to them. It will act as an aide memoir and help them to keep focused on actions. It might provide useful contact details for other services or support. It will also remind them what they need to do if something goes wrong.

Services need to consider how information will be recorded and how it will be presented. There are two very separate sets of requirements in recording the care and support planning conversation:

1. ***The personalised care and support plan for the individual and their carer.*** This should be written in plain English, avoiding jargon and clinical terms, and should be written to help support their self-management. It might include a summary of their needs, goals and actions; what support and services are in place or are being arranged; and names and contact information for key links, such as their named GP or care co-ordinator.



A good example of a personalised care and support plan for patients and carers to use is available at <http://www.myhealthplan.see.nhs.uk/>

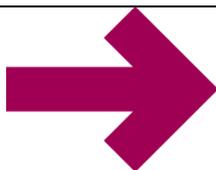
2. ***The personalised care and support plan as part of the clinical record, to assist care professionals in delivering care and support.*** Having information about the individual's care and support plan included in their clinical record is important for a number of reasons. It demonstrates that a conversation about their care and support needs has taken place. It records key information which multidisciplinary teams may need to be aware of in providing care and support. And it can also provide useful data on the health and care needs of the patient population, the services they are accessing, and any unmet needs.

There are different options for recording care and support plans:

- **Information presented in paper copy** – paper copies of care and support plans can be held by the individual and/or their carer and they can choose whom they share it with. Plans can be a simple document with a summary of information, or they can be detailed and personalised, incorporating individual reflections, pictures and photographs. Examples of hand-held paper records include maternity records and personal child health records (Red Book) and the summaries of priorities, goals and actions designed by the Year of Care Programme teams.



- **Information recorded electronically using IT systems -**
  - *As part of the clinical record* – the care and support plan may be recorded as notes in the clinical record. The GMS contract in England for 2014/15<sup>7</sup> includes the requirement for GP practices to enable patients to access their own records. GP practices can choose how much information from the clinical record is available for patients to view and could choose to allow full access or access to notes and test results to enable patients and carers to have more control over their own information. However, it is important to note that viewing and printing out information directly from the clinical system might not present a very accessible document for the individual or carer and may require explanation of the terminology.
  - *Care plan created using a template on the clinical system* – services can develop templates within the clinical system, or using standard IT packages such as Microsoft Word. These documents can more clearly be defined as a care and support plan and can be printed out or emailed to the individual and their carer.
  - *IT applications to help people manage their health, care and wellbeing.* There are personal health record systems available which patients and carers can access to record the information they want. It is possible for some of these systems to link with the clinical record, but information is presented to the patient and carer in a more accessible format. These systems will normally be commissioned by local organisations. There are a number of different systems including [HealthFabric](#), [VitruCare](#), and [My Health Plan](#).



### **Case study: Online goal setting and action planning**

[VitruCare](#) is an internet based self care service that supports patients to make decisions about their lifestyle based on their electronic health record.

Patients set their own goals and develop action plans to achieve them, selecting trackers to help monitor their progress. The plan is discussed with their GP and set into action. GPs can then act as coaches, helping patients to follow their action plan.

The approach relies on taking a whole life view together with the patient, who then goes on a new journey of self-care, with signposts provided by the care team. As the service is highly personalised during the goal setting and action planning process, patients are motivated to change. They feel more in control of their health, find the results self-reinforcing and become more accountable for their health, as they become 'activated to self-care'.

For the GP, the integration with their clinical system ensures that the patient uses clinical data taken directly from the electronic health record. Screens give direct access to their patients' action plans, allowing clinicians to discuss the appropriateness of goals and action plans for clinical safety. It is convenient to stay in touch with patients and keep an eye on progress of the whole LTC practice.

Bradford CCG has commissioned the service for 15 practices. The service has helped to reduce the number of patient visits to GP practices, which benefits both the patient and the practice. It can help to get the most complex patients with multiple long term conditions involved in goal setting and action planning, engaging in communication and ultimately, making better choices for their lifestyles, tracking and sharing their results. Early results show improved outcomes for patients with significant reduction in their weight, blood pressure, blood sugar and HBA1c after using the system for six months.

A more detailed case study is available [here](#).

Some key considerations for documenting care and support plans:

- **What format will you use to share care and support plans with individuals and carers?** Will you use paper or electronic formats? How can you take into consideration what format works best for the individual?
- **What format will you use to share care and support plans with multidisciplinary teams?** Can you share information via clinical systems?
- **What systems will you use to record care and support plans as part of the clinical record?** Will plans be attached as separate documents, or incorporated into the clinical record?

### 5.3.2. Developing templates and datasets

Whilst conversations should remain flexible, and the topics discussed will vary for each individual, it may be helpful to create templates for recording care and support plans. Templates should not be used as a checklist but to aid recording of key information. The *discussion* about care and support comes before the *documentation*.

Below are some examples of information headings that could be included in a care and support plan template. This list is not mandatory or exhaustive, it is purely illustrative. You may choose to record different information, or create templates for different situations.

- Record details – including consent status, date of care and support planning discussion

- Details about the person
  - Their name, contact details, date of birth, NHS number, next of kin
  - Do they have any communication and access support needs e.g. need for interpreter, preferred spoken language, functional status, disabilities, specific requirements e.g. postural support
  - Are they the key decision maker or is their carer?
- Patient and carers views including for example, what is important to them, perceptions about their health and care, areas of concern, their preferences and priorities
- Professional's view including for example, medical history, recent test results, current diagnosis, areas of concern, priorities
- Medication - current medication and possible side effects, allergies and adverse effects
- Care and support arrangements
  - Details about what care and support arrangement have been agreed and who will be providing them including health and social care services, schools, carers, voluntary sector services etc.
  - Contingency planning including crisis care planning, identifying trigger points and early warning signs
  - Details of additional sources of support e.g. family, peers, community
- The goals and outcomes that the person has identified
  - Description of the goal
  - Status (achieved, on hold, not achieved, abandoned)
- Action plan
  - Description of action
  - Level of confidence
  - What additional support is needed?
  - What are the barriers to achievement?
- Unmet needs
  - Details of any needs that cannot be met through the care and support plan i.e. services not available locally
- Review details including dates and comments

### **5.3.3. Additional information**

Depending on the individual's needs, and which service or type of care practitioner that is facilitating the care and support planning discussion, there may be a great deal more information that is discussed and recorded, such as:

- How does the person communicate and interact – verbal, non-verbal, gestures, body language, attention span, noise levels
- 'Challenging behaviours' and their triggers
- Key medical events from the past 12 months
- Vision, hearing, mobility, dexterity (fine/gross)
- Legal & financial information (funding, personal allowances/budgets, benefits, solicitors, Independent Mental Capacity Advocacy)
- Diet – allergies, adaptive aids, dysphagia
- Social networks

- Recreational & leisure activities
- Spiritual & cultural needs
- Employment – voluntary/paid
- Equipment needed e.g. hoists, wheelchairs

There are also specific conditions or situations where different information is recorded, such as:

- **End of Life** - There is an agreed [information standard](#) which sets out what and how information should be added to the clinical record when recording preferences for end of life care on Electronic Palliative Care Co-ordination Systems (EPaCCS). This includes information such as: "Just in case box"/anticipatory medicines; preferred place of death; whether Person has made an advance decision to refuse treatment; and name and contact details of Lasting Power of Attorney.
- **Personal health budgets** – Care and support plans are central to someone's personal health budget. In addition to the information outlined above, there are some additional elements that should be included for personal health budgets<sup>8</sup>. For example, plans should:
  - Risk assessment and mitigating actions, including a contingency plan
  - Budget available, how it will be held and managed, and how it will be used
  - Monitoring and review arrangements

#### 5.3.4. Joint care plans

Where possible, care and support plans should take into consideration other plans that the individual has, combining these wherever possible in order to support person-centred co-ordinated care. This will particularly apply to people who are receiving support from both health and social care services, and for children and young people with special educational needs who have an Education, Health & Care plan to consider their needs and the support they require across school, health and social care.

When considering what information to include in a joint health and social care plan, consideration needs to be given to social care requirements and the different contact points that people have with the system. Information might include:

- Details of needs assessments;
- Whether, and to what extent, the needs meet the eligibility criteria;
- Which needs will be met, by which services, and how
- For a person needing care, for which of the desired outcomes care and support could be relevant;
- For a carer, the outcomes the carer wishes to achieve, and their wishes around providing care, work, education and recreation where support could be relevant;
- The personal budget;
- Information and advice on what can be done to reduce the needs in question, and to prevent or delay the development of needs in the future;
- Where needs are being met via a direct payment and the amount and frequency of the payments.

### 5.3.5. Agreeing plans and signing them off

In order for care and support plans to be effective and actionable, the individual, their carer, and the care practitioners explicitly mentioned in the plan must agree to the factors within the plan, and how the needs in question will be met. This agreement should be recorded as part of the plan. However, it is important that the individual and their carer do not feel that this is a 'contract' and that they will be penalised for failure to achieve goals.

In some situations, signing off plans may require approval from additional governance procedures. For example where the individual has a personal health budget and is using this in more unusual ways, the identified solutions may require approval from a separate panel. Local processes should set out who will sign off care plans and who can be consulted in order to reach a decision if there are difficult decisions to make (e.g. risk enablement panels). It should be noted that approval panels can take time and add additional bureaucracy and so where possible, organisations should develop their own protocols for dealing with particular decisions or risks.

It is necessary for all parties to know what will happen if there is disagreement about signing off a plan, and to have in place a clear process of appeal. If a plan cannot be signed off, then clear guidance for how it needs to be amended should be given.

Some key considerations in agreeing and signing off care and support plans:

- **How will you record that all parties have agreed to the care and support plan?** This may form part of the care and support plan template, or may need to be captured in a separate document.
- **What processes will you put in place for signing off plans that impact on multidisciplinary teams, have higher risk scores, or involve innovative use of services?** Are there existing governance structures and protocols or will new arrangements be needed?

## 5.4. Step 4: Review

Personalised care and support planning should be a continuous process, not a one-off event, and it is important to review what is working and what is not.

### 5.4.1. How and when to update personalised care plans

As part of the care and support planning, there should be a discussion of when and how the plans should be reviewed. The time between reviews will vary depending on the individual's health and circumstances but should be reviewed at least annually.

The frequency of reviews should be responsive to individual need. For example, more regular reviews may be required for people who are particularly isolated; have a degenerative or fluctuating condition; lack mental capacity; or where other particular risks are identified during care planning that may need more regular monitoring.

Additional reviews or offers of review should be triggered by key events, for example, discharge from hospital, new diagnoses, social issues, bereavement or changes to social care support. For people with fluctuating conditions, a more flexible approach may be needed with the frequency and number of reviews being determined by the patient. Carers should also be able to trigger a review.

The review discussion may result in changes to the plan or even be an opportunity for the person to opt out of the care and support planning process. As with the original care planning discussion, the individual, their carer and the care practitioner will need to prepare for the discussion to consider what is working well, what is not, and what might need to change.

There should be no surprises during a review of the personalised care and support plan and this places a responsibility on both the individual and the lead care practitioner. The review is not the time to discuss changes in diagnosis or worrying test results, such news might affect the person's ability to reflect on their wider care and support as they try to digest new information. Likewise, practitioners should be alerted about any critical incidents or crises either by other care services (bearing in mind that there can be a delay in sharing information), by the individual, or their carer/family.

#### **5.4.2. What should be covered in the review?**

The review discussion can cover issues such as:

- progress against the action plan and towards achieving their goals, both through their own self-management and through actions by others
- whether their health (mental and physical) and wellbeing has changed in any way
- whether their situation has changed in any way
- whether any unplanned or emergency care has been needed since the last discussion
- whether the care and support is working for them
- any changes that might be needed to improve their care and support
- their observations through self-monitoring about changes in symptoms, behaviours or feelings
- how confident they feel about living with their condition or disability day to day and what might help them feel more confident
- identification of new goals and actions

Any changes need to be documented in the care and support plan and a new copy given to the individual and carer.

It may also be necessary to inform other members of the multidisciplinary team of any changes.

#### **5.4.3. Learning from the review**

Although support for particular needs might be identified within a personalised care and support plan, the individual might find that this support does not work for them, for whatever reason, and is not meeting their needs. It is important to learn from this feedback as

changes to care pathways or commissioned services might be needed. This is discussed further in [Part 4](#).

Patients and carers might find it difficult to provide such feedback either because they feel they should be grateful for the support, or they feel fearful of losing services or support. They might not feel comfortable giving negative feedback to a care professional and in these circumstances, peer support might allow for a more honest conversation.

Some issues to be considered in reviewing personalised care and support plans:

- **What will be your standard offer for reviewing care and support plans?** Whilst it is important to be able to tailor the frequency of reviews to the needs of individuals, you should consider what capacity exists within the service and with partners to offer the best support to patients.
- **What mechanisms do you have in place to alert you to when a review is needed?** This will depend on your systems and processes for sharing information and for multidisciplinary working.

## 5.5. Conclusion

This section has demonstrated that there are a number of practical, strategic, and cultural considerations in introducing personalised care and support planning. As highlighted by the House of Care, training and time for reflection for care practitioners will be important, as will support for patients and carers. There are a number of system changes needed, details of which have not been covered extensively in this handbook. And of course, personalised care and support planning will rely on the commissioning infrastructure discussed in [Part 4](#), both in terms of how it is embedded into long-term conditions strategies and care pathways, but also the services and support available to help people achieve outcomes, better manage their health and wellbeing, use services more appropriately for their needs, and experience better quality of life.

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