

#PlanForLife

# **WHAT IS THE ROLE OF VOLUNTARY, COMMUNITY AND SOCIAL ENTERPRISE (VCSE) ORGANISATIONS IN CARE AND SUPPORT PLANNING?**

A discussion paper



**National Voices**

People shaping health and social care

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## ACKNOWLEDGMENTS

Thank you to all the partners who contributed to this paper, in particular members of Wellbeing Our Way's care and support planning community of practice and Year of Care Partnerships.

Wellbeing Our Way's care and support planning community of practice is a small group of voluntary, community and social enterprise (VCSE) organisations who aim to develop care and support planning within their own organisations, and make a contribution to the development of care and support planning across the VCSE sector more widely.

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## INTRODUCTION

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# INTRODUCTION

There is increasing consensus that people with long term conditions and disabilities should be supported to live the lives they want to lead, and receive the treatment, care and support they identify and need. The Care Act 2014<sup>1</sup> gives local authorities a new legal responsibility to provide a care and support plan (or a support plan in the case of a carer), based on what matters to the person and what they want to achieve.

Significant policy interest in care and support planning<sup>2,3,4</sup> establishes that a central aim of this approach is to enable people to manage their long term health condition(s) through being linked into community resources, alongside more traditional health services.<sup>5</sup>

The NHS Five Year Forward View<sup>6</sup> looks to a future health system with a new relationship with patients and communities and sets out a series of commitments in relation to empowering people, supporting carers, and engaging the voluntary sector and communities. *A new model of partnership with people and communities: key principles*<sup>7</sup> sets the expectation that care and support planning becomes the 'default mode'<sup>7</sup> as a 'key enabler of high quality care and support, especially for those with long term conditions'.<sup>7</sup>

Fundamental to this growing care and support planning mandate is the increasing recognition that voluntary, community and social enterprise (VCSE) organisations are valuable strategic partners<sup>8</sup> in developing and offering care and support planning, as well as providing 'more than medicine'<sup>9</sup> support.

This policy and practice paper aims to:

- demonstrate a range of roles for VCSE organisations in offering and developing care and support planning for people living with long term conditions and disabilities
- use case studies to illustrate existing best and promising practice: these examples offer a 'typology' of potential roles the VCSE sector can take throughout the care and support planning process
- stimulate discussion around the role of the VCSE sector in relation to care and support planning

This paper considers how VCSE organisations can meaningfully contribute to the care and support planning process, and offers practical examples of the diverse ways in which this is already happening. It argues that the knowledge, skills, experience and resources of the VCSE sector are crucial factors in developing care and support planning at scale.

This paper also argues that for care and support planning to become a widespread practice, it needs to be clearly defined in local pathways that are designed – hopefully co-designed with people with lived experience – and commissioned accordingly.

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Our intention is that this paper, and the examples of promising practice contained within it, stimulate discussion which contributes to the following developments:

- 1 VCSE organisations** have examples of different approaches to care and support planning and use this understanding as a basis for developing their own care and support planning approach
- 2 Commissioners** understand the value of care and support planning as an effective approach for enabling people to live with independence, optimism and control over their lives and invest resources to enable care and support planning to be developed at scale; this includes the development of local pathways which clearly articulate the contribution of VCSE organisations as part of the wider health and social care sector
- 3 People with lived experience** are engaged as co-designers and co-producers of the care and support provision in their area and are co-commissioners of services
- 4 People with lived experience** are empowered to ask their health and care professionals to support them in developing their own personal care and support plan

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# CARE AND SUPPORT PLANNING WITHIN COORDINATED CARE

Health and care communities need to ensure that care and support planning is included in local pathways which enable staff from across the health and care system, including the VCSE sector, to understand where care and support planning fits and how they are able to play their part.

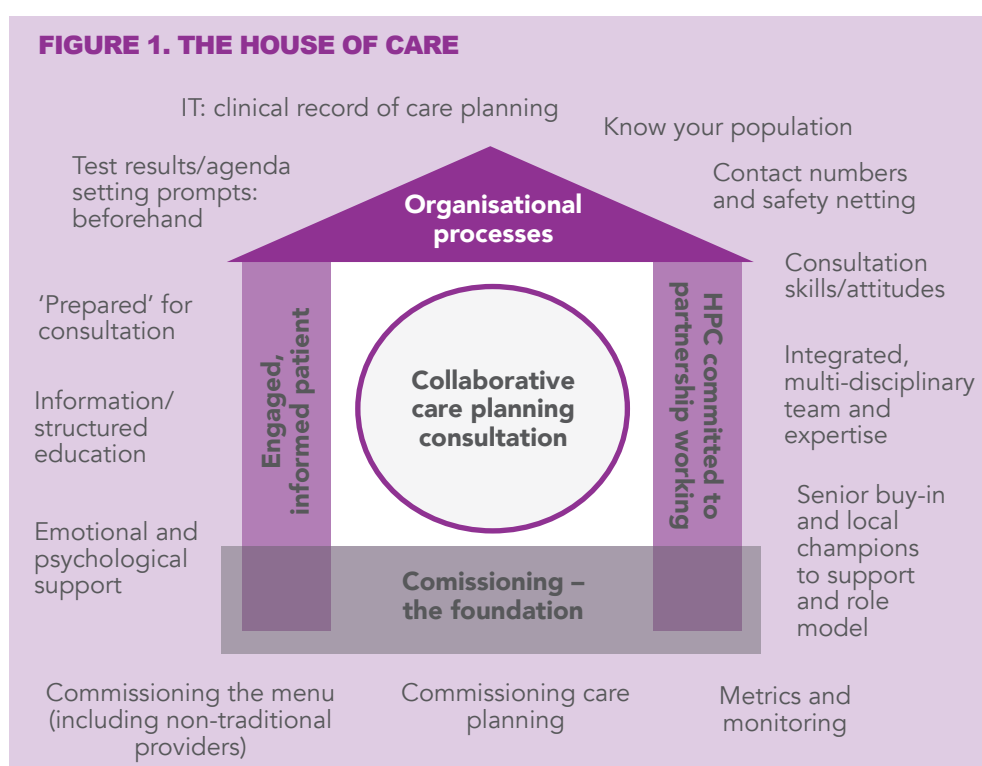
## THE HOUSE OF CARE

The House of Care<sup>10</sup> is a visual representation of the elements that need to be in place to deliver effective care and support planning.<sup>10</sup> It demonstrates the interdependence of each element: each aspect needs to be in place in order for care and support planning to work. The House of Care can be used as a checklist or a flexible framework for the care and support planning process to be developed around the needs of local people.

Care and support planning works most effectively when it is:

- integrated with routine care and part of clearly defined local pathways. in particular, ensuring that the person's usual doctor is involved and informed<sup>11</sup>
- comprehensive: care and support planning needs to be part of a continuous cycle of 'normal' care and not a one off process, with attention paid to the quality of each stage<sup>5</sup>
- well supported: training, supervision and support for clinicians as well as patients<sup>12</sup>
- supported at a senior level, ideally linked with commissioning 'right from the top, right from the start' right the way through.<sup>13</sup>

**FIGURE 1. THE HOUSE OF CARE**



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# WHAT IS CARE AND SUPPORT PLANNING & WHY DOES IT MATTER?

## WHAT IS CARE AND SUPPORT PLANNING?

Care and support planning is a way that people with long term conditions and disabilities can work together with their health and social care professionals, and/or other supporters. It starts with what matters to the person and identifies the best treatment, the right care and support and the actions they can take themselves to help get there.

Care and support planning is the route for many people living with long term health needs to access community approaches such as advocacy, self-management support, activity groups, befriending, one to one coaching, mental health recovery, education and information, and so on. It can usefully be thought of as the key access point which enables a person to manage their care and treatment, and access a range of 'more than medicine'<sup>14</sup> and person centred approaches to enable them to manage their health and wellbeing more effectively. Care and support planning is also the process by which people are enabled to access social as well as physical support through their personal budget.<sup>15</sup>

The Department of Health describes care and support planning as a process which can help decide the best way to meet the person's needs. It 'considers a number of different things, such as what needs the person has, what they want to achieve, what they can do by themselves or with the support they already have, and what types of care and support might be available to help them in the local area'.<sup>16</sup>

## THE FOUR STEPS OF CARE AND SUPPORT PLANNING

Working closely with national organisations including the Year of Care Partnerships team and our members, National Voices has developed Care and Support Planning Resources,<sup>17</sup> including the Guide to Care and Support Planning<sup>18</sup> and a series of short films.<sup>19</sup>

The care and support planning process entails four main steps:<sup>20</sup>

### 1. Prepare

This stage is about:

- thinking about what matters most to the person
- sharing any useful and important information before the discussion, including medical information and treatment, care and support options<sup>21</sup>

### 2. Discuss

This stage is about:

- the person and their care and support partner working together
- conversations exploring the person's strengths, goals and priorities
- discussing any existing support which is enabling the person to live well

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- exploring what care and support the person may need from other people or services
- consideration of the person's future needs, including potential deterioration or fluctuation in their health
- where appropriate, this should include advance care planning to enable the person to share their wishes in the event that they become unable to make their own decisions or communicate their wishes.<sup>21</sup>
- planning the review process so that this meets the person's needs and preferences
- supporting the person to be as active a member of their community as they wish.

**3. Document**

This stage is about:

- recording the main points from the care and support planning conversation
- making sure that the plan belongs to the person and is easy for them to understand and use
- ensuring that the plan is shared with the person's clinical and social care professionals, or multi-disciplinary team, as appropriate.

**4. Review**

This stage is about:

- reviewing whether the person's needs have changed
- reviewing what's going well, what's not going well and making any changes to the plan
- reviewing the person's personal budget where appropriate.

Think Local Act Personal's care and support planning tool<sup>23</sup> maps the principles of care and support planning across a variety of complex physical and mental health and social care scenarios and shows that the principles and steps are generic.

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**WHO BENEFITS FROM CARE AND SUPPORT PLANNING?**

There are a number of approaches to identifying which cohorts of people may benefit most from care and support planning. The following table helpfully summarises the benefits and risks of a number of these approaches.<sup>24</sup>

**TABLE 1. METHODS FOR IDENTIFYING PATIENTS**

APPROACH	BENEFITS	RISKS
Top-down risk stratification.	Take a whole population view.	The top 2% with highest risk of admission may not be the best suited to CC&SP model.
Segment into cohorts (eg frailty index, disease specific).	Allows incremental up-scale, is a natural starting point.	Risks excluding people with high risk that are not in the cohort.
Organic identification by practices.	GPs know their population better than anyone.	Does not take a whole-population view meaning health inequalities are a risk.
Identify and work with patients with <i>higher</i> levels of activation.	Provides opportunity to gather evidence of benefits early on to encourage work later with the less activated.	Delay in working with less activated patients, who may benefit as much, or more, from the process.
Identify and work with patients with <i>lower</i> levels of activation.	People who are already more 'active' in relation to their health and wellbeing (who understand the care process and have the knowledge, skills and confidence to take on the role) are more likely to choose preventative health behaviours. Working with the less 'active' could reduce health inequalities.	Risks can exclude people with high risk who are not in the cohort.

Different approaches, or indeed combinations of approaches, may suit particular community needs. It is essential that full consideration is given to the potential impact on health inequalities, to ensure that care and support planning helps to reduce these inequalities.<sup>25</sup> Indeed, care and support planning can be an effective prevention tool and help to reduce health inequalities.<sup>26, 27, 28</sup>

Care and support planning is already being offered to diverse cohorts of people by VCSE organisations. For instance, Macmillan Cancer Support and the Bromley by Bow Centre have developed a social prescribing service which is being delivered from secondary care.<sup>29</sup> VCSE organisations are involved in enabling people to make use of personal budgets, both through existing local authority programmes, as well as through Integrated Personal Commissioning.<sup>30</sup>



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There is evidence that care and support planning leads to improvements in physical and mental wellbeing, and that it enables some people to increase their self-management capability.<sup>31</sup> It also improves people's experience of care, as well as the job satisfaction of health and care professionals.<sup>32</sup> Care and support planning has been shown to lead to a more efficient and sustainable use of resources.<sup>33</sup>

Age UK's Personalised Integrated Care programme<sup>34</sup> enables older people to identify their own goals, and to access a combination of medical and non-medical support to support them in working towards their goals. This approach has resulted in people reporting higher levels of emotional wellbeing, and a reduction in unplanned hospital admissions.<sup>35</sup>

Compassion in Dying's *My Life, My Decision* is an outreach service to support people aged over 50 to ensure their wishes for treatment and care are known and respected. In its first year, the project found the following:

- 75% of service users who completed a planning ahead tool (such as an Advance Decision or Advance Statement) stated they felt happier about the future or had greater peace of mind after they planned ahead for their future treatment and care.
- 75% of service users who completed a planning ahead tool (such as an Advance Decision or Advance Statement) stated that doing so reduced some worries or anxiety.
- 62% of service users who completed a planning ahead tool (such as an Advance Decision or Advance Statement) reported that after doing so they felt more confident that their wishes and preferences would be known by their carers and doctors.
- There is also evidence that planning ahead in advance of a loss of capacity gives people peace of mind, and evidence to suggest that discussing and meeting individual preferences at the end of life increases the chances of having a 'good death'.<sup>36</sup>

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# CARE AND SUPPORT PLANNING PARTNERS

National Voices' Guide to Care and Support Planning<sup>37</sup> describes a care and support partner as an individual who works with the person throughout the care and support planning process. Their role is to support the person to identify what matters to them, their existing strengths and support, and what additional care and support they may need.

For many people, the care and support partner could be a GP, practice or specialist nurse, social worker, physiotherapist or other health or care professional. The person may identify a peer supporter or trained volunteer, either as someone to support them throughout the care and support planning process, or as someone who can help put the plan into practice, in order to better manage their health and wellbeing.<sup>38</sup> Peer supporters may be an effective link into community resources, including those delivered by VCSE organisations.<sup>39</sup>

The care and support planning partner must be able to link to and have responsibility for the person's individual clinical need. One approach to ensuring that the VCSE can contribute while ensuring that the person's clinical needs are fully addressed is for VCSE organisations to become part of the person's multi-disciplinary team; Age UK's Personalised Integrated Care programme is demonstrating the benefits of this approach.<sup>40</sup> Think Local Act Personal has found that care and support planning works best when it takes place within a multi-disciplinary team, often but not always revolving around general practice.<sup>41</sup>

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# THE ROLE OF VCSE ORGANISATIONS IN THE DIFFERENT STAGES OF CARE AND SUPPORT PLANNING

This section considers the diverse potential roles of the VCSE sector throughout the care and support planning process. It offers a 'typology' of activities, both by stage of the process, and also in relation to the process as a whole (in terms of leadership and codesign for instance).

The table on page 11 provides an 'at a glance' overview of some of the ways in which VCSE organisations can support a person throughout the care and support planning process.

## Stage 1 - Prepare: getting ready for care and support planning

There are many ways in which VCSE organisations can enable people to plan for their care and support planning conversation. These include:

- providing information around the person's condition and the choices which may be open to them
- support to understand and engage with the process
- enabling confidence in order that the person is able to set their own agenda
- supporting people to access peer support as an important first step to the person deciding what matters to them and as an opportunity to 'normalise' their experience
- VCSE organisations can also be a useful link between the person and their clinicians, helping them to ask for, and understand, test results and health assessments before they have their care and support planning conversation.



### CASE STUDY

#### MY CROHN'S AND COLITIS CARE: YOUR GUIDE

**CROHN'S &  
COLITIS UK**

My Crohn's and Colitis Care: Your Guide<sup>42</sup> aims to support people living with Inflammatory Bowel Disease (IBD) to get the best out of their healthcare by working in partnership with those supporting them. The guide sets out what people can expect from a good IBD service and how people can work most effectively with their local health service to manage their condition and care. The guide may also be helpful for friends and family of those living with IBD so they can support the person to make decisions about their treatment and care. By enabling people to understand their choices and what 'good' looks like, this guide may be a helpful resource for people preparing for their care and support planning conversation.

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**TABLE 2. AT A GLANCE OVERVIEW OF SOME OF THE WAYS  
IN WHICH VCSE ORGANISATIONS CAN SUPPORT A PERSON  
THROUGHOUT THE CARE AND SUPPORT PLANNING PROCESS**

STAGE OF THE CARE AND SUPPORT PLANNING PROCESS	POTENTIAL ROLES OF VCSE ORGANISATIONS
1. Prepare	<ul style="list-style-type: none"> <li>• Providing information around the person's condition and the choices which may be open to them</li> <li>• Support to understand and engage with the process</li> <li>• Enabling confidence in order that the person is able to set their own agenda</li> <li>• Supporting people to access peer support as an important first step to the person deciding what matters to them and as an opportunity to 'normalise' their experience</li> <li>• VCSE organisations can also be a useful link between the person and their clinicians, helping them to ask for, and understand, test results and health assessments before they have their care and support planning conversation.</li> </ul>
2. Discuss	<ul style="list-style-type: none"> <li>• The person may identify someone working within a voluntary or community organisation to support them in their care and support planning discussion. For instance, this could be a health coach or a peer supporter.</li> <li>• VCSE organisations may also provide advocacy support to ensure that people are genuinely involved in discussions and know their entitlements; and to maintain a focus on strengths and aspirations.</li> </ul>
3. Document	<ul style="list-style-type: none"> <li>• Offering practical and motivational support around using apps to record and maintain their plan.</li> <li>• Supporting the person to use a paper-based record which provides space for the person to keep clinical records, record questions to raise with their clinicians and to share their priorities with their health and care professionals</li> <li>• Enabling the person to record their plan in a creative format which makes sense for them; for instance by using their usual communication tools as a basis for recording their plan in a way they can understand</li> </ul>
4. Review	<ul style="list-style-type: none"> <li>• VCSE organisations can play a key role in ensuring that reviews focus on what matters to the person, and happen in ways which enable the person to express their views about what's going well, as well as what needs to change. The person centred review process is an effective model for ensuring that reviews are person led, rather than service driven. Reviews should enable the person and their professional team to consider their full range of social and clinical strengths, needs and support.</li> </ul>

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The person may identify someone working within a voluntary or community organisation to support them in their care and support planning discussion. For instance, they may already be working alongside a health coach from an organisation like My Health My Way<sup>43</sup> in Dorset, or identify a staff or peer facilitator from a self management programme as their care and support planning partner.

The VCSE sector has a long and valued history of providing advocacy support, in particular to ensure that people are genuinely involved in discussions and know their entitlements, and to maintain a focus on strengths and aspirations. This could be a significant contribution to ensuring that care and support planning conversations consider the person's social, emotional and wider wellbeing interests, alongside their clinical need.

**CASE STUDY****CIRCLES OF SUPPORT  
FOR PEOPLE LIVING WITH DEMENTIA**

NDTi and Innovations in Dementia worked together to introduce Circles of Support as a way of supporting people with dementia to maintain their connections in 4 areas across the south of England. Circles of support are a means of people coming together around an individual with support needs, to plan and ensure the person can achieve the life they want. The project aimed to learn how these could work best for people with dementia.

Ideally a circle of support is made up of a group of family, friends and professionals who are in the person's life. They work best when there is someone to facilitate or coordinate the group, including meetings when the group come together to consider how a person with dementia can be supported to maintain their connections and to continue doing what matters most to them. This may be a professional involved with the person such as a memory advisor, a support worker, volunteer or family member.

The person is supported to think through how they want their life to be, and plan for life now and in the future using person-centred approaches. This involves finding out what the person would like to change in their life, what is important to them, what aspirations they may have and how they can best be supported to achieve them. With the person at the centre of conversations, people in the group plan how they can support the person to achieve their wishes. Planning takes into account the person's health and social care support needs, and work out how a range of natural support (e.g. families and friends) as well as professional support (e.g. home carer) can help the person live the life they want. The person may also have a written care and support plan which builds on the planning with the individual and their circle, or is developed as part of a circles of support discussion.

The project found that some people's natural networks of support had shrunk following a diagnosis of dementia and they needed support to

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**CASE STUDY CIRCLES OF SUPPORT  
FOR PEOPLE LIVING WITH DEMENTIA** continued

rebuild their circle. In some cases this led to groups forming, focusing on shared activities such as a walking group and a London outings groups. In other cases people with dementia and their main carers, often a son, daughter or spouse, wanted to have places to go where they felt safe with peers who were also people with dementia and carers. In other situations, planning was focused on working out the way to best avoid the person having to move into care, maintaining employment, or increasing activities, looking at how everyone in the circle could come together to provide support to the individual. One of the key benefits of having a circle of support who really understood what matters to the person, was that the person and their carer did not feel alone when help was needed, and crises were often avoided.

By enabling people to understand their choices and what 'good' looks like, this guide may be a helpful resource for people preparing for their care and support planning conversation.

**CASE STUDY  
ME FIRST**

The Me First project aims to put children and young people at the centre of the conversations about their health and healthcare. Children and young people say that good communication is more than eye contact or body language. It is about involving them in choices and decisions, drawing on their experience and expertise about their own health, and enabling them to feel in control of their healthcare.

*"Decisions should be made with us, not about us, no matter how big or small, because they are about our bodies and our lives."*

We know this is important for people of all ages, but this is a particular challenge for children and young people, who say that all too often that:

- Communication is between healthcare staff and their parents
- Their involvement in healthcare conversations is often limited to non-health related issues and they are less involved in discussions about treatment or making choices and decisions.
- They are not asked how things should happen
- Adults use complex language that they struggle to understand
- If they are assertive, knowledgeable, or ask questions then this is often misread as them being difficult or challenging
- Co-developed with children, young people, and healthcare professionals, the Me First project has developed a new range of training and online resources to improve communication between children, young people and healthcare professionals.



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The Me first communication model<sup>44</sup> provides a practical framework to support children and young people centred conversations in healthcare. Based on a review of the research on person centred communication,<sup>45</sup> we believe this is one of the first healthcare communication models of its kind, designed for and with children and young people.

The Me first website<sup>46</sup> contains an interactive communication model to enable healthcare professionals to build their own conversations and apply the model to their practice; a resource hub, which enables users to share tools, projects, and ideas from throughout the UK; and practical advice and tips from children, young people, and healthcare professionals about how to put the model into practice.

The Me first masterclasses,<sup>47</sup> which are co-delivered with young people and support healthcare professionals to apply the Me first communication model to their practice. The training builds on attendees' existing skills and expertise, and utilises quality improvement techniques to enable healthcare staff to embed learning in their clinical practice. The masterclasses have been incredibly well received, with 100% of participants rating the training as good or excellent and the emerging findings from the independent evaluation showing the training is making a lasting difference to participants' communication skills.

By enabling people to understand their choices and what 'good' looks like, this guide may be a helpful resource for people preparing for their care and support planning conversation.

**Stage 3 - Prepare: getting ready for care and support planning**

VCSE organisations can play a significant role in helping to ensure that the person's plan is recorded in a way they can understand and use, and they hold a copy of their plan.

There are a range of ways in which VCSE organisations can ensure that the person has their plan in the most appropriate way for them:

- Offering practical and motivational support around using an app such as Health Fabric<sup>48</sup> to record and maintain their plan.
- Supporting the person to use a paper-based record such as *My Plan for Life*<sup>49</sup> which provides space for the person to keep clinical records, record questions to raise with their clinicians and to share their priorities with their health and care professionals.
- Enabling the person to record their plan in a creative format which makes sense for them; for instance by using their usual communication tools as a basis for recording their plan in a way they can understand.
- Enabling confidence in order that person is able to set their own agenda.

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Epilepsy Action has developed My Epilepsy Care Plan,<sup>50</sup> a straightforward and easy to use patient-held care plan for people with epilepsy to complete. The plan is a PDF resource, which can be downloaded online or ordered in hard copy from the charity's online shop. It explains the benefits of care and support planning for people and carers; how to get started with relevant health and care professionals; and how they may want to share the information with others, whether professionals, friends and family, employers or schools and colleges. The plan includes sections to record details of the person's care, support and treatment, including medicines, as well as a section which focuses on the person's individual goals, the steps they will need to take to achieve these, and the support they will need from others, with a space to review and record progress. A Welsh language version is also available.

Epilepsy Action includes the My Epilepsy Care Plan within their suite of resources for professionals, to encourage them to adopt a care and support planning approach with their patients. Epilepsy Action also offer an electronic care plan template that professionals can download from our website/SystmOne or EMIS.

The primary care resource pack contains a section on empowering patients, highlighting relevant guidance and best practice relating to care and support planning. The resource pack on epilepsy in pregnancy for obstetrics professionals<sup>51</sup> also includes a careplan to record essential medical details to add to a mum-to-be's antenatal notes, along with several factsheets about epilepsy and pregnancy. The charity is currently considering the development of paediatric care plans.

Alongside the provision of advice and information services, Epilepsy Action offers training to enable people with epilepsy and professionals to engage in care and support planning. Motivational interviewing training is being provided for epilepsy nurses, while a new 8 week online self-management programme for people with epilepsy is being evaluated by Coventry University and is using QOLIE-31 (epilepsy specific measure) and the Patient Activation Measure (PAM) to demonstrate patient outcomes.

**Stage 4 - Review: checking on how things are going**

VCSE organisations can play a key role in ensuring that reviews focus on what matters to the person, and happen in ways which enable the person to express their views about what's going well, as well as what needs to change. The person centred review process is an effective model for ensuring that reviews are person led, rather than service driven. Reviews should enable the person and their professional team to consider their full range of social and clinical strengths, needs and support.



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Community Integrated Care is one of the UK's largest health and social care charities. It works in the community, delivering life-enhancing support to people with a diverse range of care needs, including learning disabilities, mental health concerns, autism, age-related needs and dementia. Community Integrated Care aims to support people leaving long stay, institutionalised hospitals to lead fuller, better lives in the community.

In 2015, Community Integrated Care worked with Helen Sanderson Associates to introduce person-centred reviews across the organisation.

The person-centred review process encourages and supports people to think about who they want to invite to come along to their meeting to help them plan for the life they want to lead. Crucially, the reviews are person led, rather than service driven.

Reviews use person-centred thinking tools and begin by asking what people appreciate, like and admire about the individual and as this can have a profoundly positive effect on some people's self-esteem. From there, reviews explore what is important to and for the person. They consider the person's aspirations and what is working and not working in supporting people to meet their personal outcomes as detailed in their care and support plans. The approach then leads on to supporting people to think about how they want to spend their personal budgets.

A careful process of exploring what's important to the person before inviting other people involved, including families, professionals and support staff to contribute and give their perspectives ensures that everyone's voice is heard, but keeps the focus firmly on the person supported. All of this rich information is then collated into a plan of action to support the changes required to ensure people get the care and support they want and need to achieve their personal outcomes.

Community Integrated Care identified 36 change makers from across the organisation to train as person-centred review facilitators. These colleagues are made up of inspirational leaders from across the organisation's six regions, who all had a particular interest in personalisation and embedding person-centred approaches in their day to day activities. After facilitating person-centred reviews themselves, these change makers have gone on to become trainers to enable other colleagues to facilitate person-centred reviews, and spreading this approach across the organisation.

Feedback from people who have held their person-centred reviews has been great. People told Community Integrated Care they really enjoyed the reviews and families and friends all commented on how the relaxed and informal approaches supported people to remain in control and enabled them to really say how they felt about their current support and to plan their personal outcomes.

This case study is adapted from Helen Sanderson Associates' blog: What are we learning about introducing person-centred reviews at scale, which includes further detail about person-centred reviews.<sup>52</sup>

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Care and support planning links people into community provision, alongside appropriate clinical support. There are a range of community based or 'more than medicine' approaches, such as health coaching or peer support, which can enable people to develop their skills, confidence, knowledge and motivation around living well with their long term health needs.<sup>53</sup>

Social prescribing is one means by which GPs, or other clinical staff, can link people in with community activities which may support their emotional, physical and wider wellbeing.

Social prescribing can be a complementary approach to care and support planning in terms of putting the plan into action, in particular by:

- linking the person into community support once they have identified their strengths and goals through the care and support planning process
- identifying an appropriate person to assist the person to access resources identified in the plan, for instance a community or peer supporter
- enabling the person to record their plan in a creative format which makes sense for them; for instance by using their usual communication tools as a basis for recording their plan in a way they can understand
- enabling confidence in order that the person is able to set their own agenda.

**CASE STUDY****THE MACMILLAN SOCIAL PRESCRIBING  
SERVICE, BROMLEY BY BOW CENTRE**

The Macmillan Social Prescribing service, in partnership with the Bromley by Bow Centre, provides personalised, one-to-one support to people living with and beyond cancer to overcome practical issues and improve their wellbeing.

With increased diagnoses and longer survival for cancer patients, long term management is becoming more important. 64% of people living with cancer have practical or personal support needs, and 78% have emotional support needs; the majority (75%) of which say that these needs are caused by their cancer or cancer treatment. Yet many do not get the support they need to live as well as possible in their homes.

The Macmillan Social Prescribing service is a two year pilot, launched in September 2015, and delivered in partnership by Macmillan Cancer Support and the Bromley by Bow Centre. The service is available to cancer patients and survivors aged 18 and over who live in Tower Hamlets, Newham, Waltham Forest or City and Hackney. It can be accessed by referral through GP practices, hospitals, community organisations and self-referral.

The service is provided by experienced professionals based in the community who work with people affected by cancer to explore and



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define what is important to them, identify the local activities and resources they need and gain support to engage with these services. The service can provide support over the phone to identify local activities and support services, or can offer a series of face-to-face appointments over a six month period at venues in each borough.

The type of local activities that people may be helped to access include:

- health and wellbeing programmes (e.g. walking groups, meditation groups and complementary therapies)
- work and volunteering advice (e.g. local employment support services)
- learning and social opportunities (e.g. art classes, gardening groups and faith groups)
- practical support (e.g. debt/welfare advice and money management workshops)
- support groups (e.g. parent and carer groups and cancer support groups)

**CASE STUDY****THE ROTHERHAM  
SOCIAL PRESCRIBING MODEL**

In Rotherham the Social Prescribing Service<sup>54</sup> is delivered by Voluntary Action Rotherham (VAR) in partnership with more than 20 local voluntary and community organisations (VCOs). It aims to increase the capacity of GPs to meet the non-clinical needs of patients with complex long-term conditions (LTCs). The Service was first commissioned as a two-year pilot in 2012. In 2014-15 it was re-commissioned for a further year with an additional 3 years of service provision contracted in April 2015 and funded through the Better Care Fund. At its core a team of Voluntary and Community Sector Advisors (VCSAs) provide a single gateway to voluntary and community support for GPs and Service users. They receive referrals from GPs of eligible patients and carers and assess their support needs before referring on to appropriate VCS services. The Service also administers a grant funding pot through which a 'menu' of VCS activities to meet the needs of Service users is commissioned. The service covers the whole of the borough of Rotherham and is one of the largest of its kind, as the majority of social prescribing activity in the UK has had a much smaller geographic focus and has not provided grant funding for additional services. The evaluation found that 82 per cent of service users, regardless of age or gender, reported a positive change in their well-being within four months of being issued with a social prescription.<sup>55</sup>

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# VCSE ORGANISATIONS LEADING THE PROCESS

## THE RELATIONSHIP BETWEEN LOCAL AUTHORITIES AND THE VCSE SECTOR

Useful precedents are being developed within social care settings in terms of how local authorities are working with VCSE organisations to deliver care and support planning. Alongside in-house provision by local authorities, options include:

- The whole process of assessment, care and support planning and money management is outsourced, typically to a third sector organisation or consortium of third sector organisations.<sup>56</sup>
- Care and support planning is outsourced as a discrete function, again typically to a third sector organisation.<sup>57</sup>
- Once an assessment of need has been completed in-house, the assessment and indicative budget are shared with a VCSE organisation who supports the person to plan how to achieve their personal outcomes through the use of a personal budget.<sup>58</sup>



### CASE STUDY

#### INTEGRATED COMMUNITY BROKERAGE IN LANCASHIRE

This case study comes from *Getting Serious about personalisation in the NHS*<sup>59</sup> and indicates how statutory health and care services can work with the VCS sector to develop a care planning approach, alongside social prescribing and support to manage personal budgets.

Integrated Community Brokerage in Lancashire involves local user-led organisations (ULO) working to support up to 4,000 local people to manage their personal budgets. The ULOs, supported and coordinated through a lead provider, facilitate care and support planning, arrange support and perform key behind the scenes activity. This model is currently being used with local Clinical Commissioning Groups (CCGs) to support people with Continuing Health Care Funding to take a direct payment and will be jointly commissioned in the future by the council and CCGs to meet the needs of a broader range of personal health budget holders.

The council has also worked with three CCGs to develop Integrated Neighbourhood Teams. This involves working with 66 GP surgeries to hold regular meetings between multi-disciplinary teams of clinicians and care professionals resulting in a 'Connect4Life' service. People are connected to local assets and universal services, alongside 'medical' solutions. Once a GP makes a referral to Connect4Life, care and support planning principles are followed, regardless of the person's eligibility for social care services and there is a strong focus on linking and connecting people within their neighbourhood to a range of offers that keep them safe and well. There were over 200 referrals within the first eight months, with a reported reduction in Primary Care service usage, A&E attendance and acute admissions.

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INTEGRATED CARE PROGRAMME**

Age UK's Personalised Integrated Care programme brings together voluntary, health and care organisations in local areas to help older people who are living with long-term conditions and are at risk of recurring hospital admissions.

Age UK works with the organisations to co-design and co-produce an innovative combination of medical and non-medical support that draws out the goals the older person identifies as most important to them.

Through the programme, Age UK staff and volunteers become members of primary care led multi-disciplinary teams, providing care and support in and through the local community.

The programme was initially launched in Cornwall in 2013, and in 2015 expanded to nine sites in total, each supporting 500 to 1000 older people over the course of one year.

At the heart of the Personalised Integrated Care programme lies a pathway that brings together local voluntary and health and care organisations to help put the older person in control of their health and enable them to regain their independence and quality of life.

- It uses risk stratification to identify a specific cohort of older people with multiple long-term conditions who are vulnerable to unplanned admission to hospital.
- Using a 'guided conversation', an Age UK Personal Independence Co-ordinator draws out the goals that the older person identifies as most important to them.
- Together, they create a care plan which brings together services from across the health, social care and voluntary sectors that are appropriate for the older person's need. Effectively, the services 'wrap around' the older person, with the aim of reversing the cycle of dependency.
- Age UK volunteers can be assigned to help older people achieve their goals
- The care plan is reviewed regularly by multidisciplinary teams in a primary care setting.
- Clear safeguarding and escalation protocols are put in place to ensure that medical attention is delivered effectively and in a timely way when needed.

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The British Heart Foundation (BHF) is supporting and providing grant funding to three health and social care organisations across five pilot sites in the UK to improve services for people with Long Term Conditions (LTCs) focussing on those who live with, or are at risk of developing cardiovascular disease (CVD). The project is focusing on using a care and support planning approach as described by Year of Care. Pilot communities of practice consisting of a population size greater than 50,000 across 8-10 GP Practices and are big enough to affect change across the health and social care system.

The communities of practice are:

- Newcastle Gateshead CCG
- Hardwick CCG
- Health and Social Care Alliance Scotland (three sites in NHS Tayside, NHS Lothian, NHS Glasgow and Clyde)

The programme aims to:

- introduce collaborative care and support planning as routine care, mainly within primary care, and develop a holistic review in place of the current tick box surveillance activities encouraged by QOF.
- redesign local pathways for cardiovascular disease services, driven by care and support planning.
- develop engagement with a wider range of activities to support self-management within the community, including the third sector. The programme seeks to establish better conversations which support self-management and enable people to be more in control of their lives.

The project scope and target groups were specifically selected to address the needs of populations with health inequalities, high deprivation and high prevalence of CVD.

CVD is a complex group of diseases and conditions, affecting nearly seven million people in the UK. The condition is often long-term, comes with co-morbidities, and results in complex pathways of care – there is clear scope for care and support planning to be of benefit (Nichols et al 2012). Despite this, care and support planning has been tested in a fairly limited way with this patient group – the focus has been on other LTCs, particularly diabetes). However, there are affinities between the conditions which suggest that the House of Care will also work well with CVD, which increasingly occurs alongside other LTCs. Consultations should be framed around patient priorities and begin with the sharing of results, discussing risks and working with people how best to achieve the outcomes important to them.

BHF is providing grant funding, project management, support to self-evaluate and training support via the Year of Care Partnership to projects sites. The programme aims to embed the House of Care – a whole-system approach to establishing, implementing and sustaining



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a new model of care based around collaborative care and support planning (CSP) in the sites in England and Scotland. Ultimately, the programme aims to ensure that individuals with cardiovascular disease engage in a collaborative care and support planning consultation, focussed on what is important to them, where they are supported to access a wide variety of community and voluntary sector activities and services.

**CASE STUDY****MACMILLAN CANCER SUPPORT –  
ELECTRONIC HOLISTIC NEEDS ASSESSMENT,  
SUPPORT AND CARE PLANNING (EHNA)**

**WE ARE  
MACMILLAN.  
CANCER SUPPORT**

Macmillan's electronic approach to assessment is simple but effective. It starts with people affected by cancer, filling in a questionnaire about their concerns on a touch screen computer (a tablet). The information is then sent to a secure care planning website, where the issues affecting the person are ranked in order of priority. Using these results, health or social care professionals develop the care plan with the person, and also review data to identify trends and local service development needs.

**Background**

In 2010 Macmillan, in partnership with the National Cancer Survivorship Initiative (NCSI), began testing HNAs with 11 NHS test communities. This led to a small pilot project to trial the concept of an eHNA with four test sites. The aim of this project was to understand the impact an electronic assessment tool would have on the HNA process and its impact on assessment and care planning for the future.

The initial testing was conducted over one year, and began with scoping and developing of the eHNA tool. The sites chosen to test and develop the eHNA were Guys and St Thomas' NHS Foundation Trust, North Bristol NHS Trust, East Kent Hospitals NHS Foundation Trust, and St Helens and Knowsley Hospitals NHS Trust.

**Development**

A priority for the eHNA project was making the assessment and care planning process easier for the person affected by cancer and their healthcare professional. This in turn would allow more assessments to be carried out, more care plans to be written, and potentially more needs to be met.

A key decision at the start of the pilot project was to use tablets for the assessment process. This allows the person to complete the assessment on their own with express consent, and to highlight concerns that would be difficult to bring up in a normal conversation.

Although Macmillan took this innovative approach in using tablets,

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AND CARE PLANNING (EHNA) continued**

many of the pilot sites had no policies in place to manage and control their use, meaning that the teams trying to pilot eHNA were pioneering this technology in their Trusts. The reliance of the tablets on the availability of a WiFi signal was another unexpected area of difficulty. Many hospital areas were not covered by WiFi at all, or the coverage was patchy at best. Trusts worked hard to overcome this, and tablets and WiFi are now more widely accepted and established.

Alongside the technical issues information governance (IG) requirements around storing identifiable NHS data within the NHS network prompted further development to ensure the eHNA met with Trust and national policy.

Macmillan sits outside of the NHS network, and consequently has no access to individual identifiable data – this is restricted to the Trust that carried out the assessment. However, it is recognised that there is tremendous value in having access to aggregated data to identify areas of concern, and more importantly to highlight potentially unmet needs. This data is an exciting new area that could in time lead to the delivery of a more timely and effective range of services to the people who need them the most.

**Progress so far**

A report from Ipsos Mori provides snapshot results of a survey looking at people's experiences of completing an eHNA, HNA or neither assessment (to provide a counterfactual argument). A very brief overview of some of the main findings is provided below.

Most people living with cancer, particularly those who completed an eHNA, felt that they had received support at the right time:

*'I'm not sure there's ever a good time, but for me at that particular point I knew I was going to be having surgery and it was a good time to think about what I was going through.'*

The holistic needs of people living with cancer appear to be better met for those who have completed an electronic assessment, compared with those that recall completing a paper assessment or can't recall an assessment at all.

*'I remember it being quite interesting because it covered a lot of things I didn't think we would talk about – emotional as well as physical needs really.'*

**Benefits to people living with cancer:**

*'Having a CNS supporting my treatment made a huge difference. Even now treatment has finished, I still require physical and psychological support, which has been highlighted and demonstrated by the Holistic Needs Assessment.'*



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## CASE STUDY

RETHINK DEVON COMMUNITY  
OPPORTUNITIES AND RECOVERY PATHWAYS

Rethink Devon Community Opportunities provides short term, goal focused, one to one support through Assistant Mental Health Recovery Workers. They accept referrals from services as well as self-referrals. The initiative also facilitates peer support across Devon and people who have been through the initial one to one recovery support often go on use the peer support groups.

At the initial assessment meeting the person is helped to identify different aspects of their life, their interests and what they would like to work on. Following this the recovery worker and the individual discuss how best the goals could be achieved and create a support plan. As well as enabling the person to gain or regain skills in order to achieve their goals, sustainability is addressed through signposting and using community resources and activities so they can enjoy meaningful activities, social contact and a fuller life.

The service uses the 'Recovery Pathways Menu' that starts with initial coaching and goal setting using a framework of practical and gradual steps to having a fulfilling and enjoyable life. The second element is known as 'mind-based pathways', that is the therapeutic and training support needed to achieve identified goals and gain confidence and independence. As part of this the organisation uses the 'Wellness Recovery Action Plan (WRAP), an approach to longer term mental health management developed by people with lived experience.

This example was originally published in *No Assumptions: a narrative for personalised, coordinated care and support in mental health*, National Voices/TLAP, August 2014.



## CASE STUDY

COMPASSION IN DYING'S  
MY LIFE, MY DECISION PROJECT  
AND MYDECISIONS WEBSITE

Compassion in Dying run the national lottery-funded My Life, My Decision project,<sup>61</sup> delivered in partnership with seven local Age UKs across England. The project provides 1-2-1 support in the community to older people, helping them set out their wishes for care and treatment, and to complete Advance Care Planning documents. (Compassion in Dying provides template Advance Decision and Advance Statement forms, and offers in-depth support to complete the documents through their Information Line.) The project also raises awareness of people's rights to plan ahead amongst the public and health and care professionals. This work is delivered by both paid staff and volunteers.

Compassion in Dying have also launched MyDecisions,<sup>62</sup> a website that supports people to draft an Advance Decision or Advance Statement online. Built in consultation with over 300 service users, MyDecisions

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guides people through different scenarios and questions to help them consider what matters most in relation to their future treatment and care. At the end people get a personalised Advance Decision or Advance Statement to print, sign, witness and share.

The charity also delivers training to professionals and has produced a toolkit for health and social care professionals to support their understanding of Advance Decisions.

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# **VCSE ORGANISATIONS INFLUENCING POLICY ASPECTS OF CARE AND SUPPORT PLANNING**

The National Development Team for Inclusion (NDTi) is a not-for-profit organisation concerned with promoting inclusion and equality for people at risk of exclusion and who need support to lead a full life. It has a particular interest in issues around age, disability, mental health and children and young people. NDTi, alongside Helen Sanderson Associates, was commissioned by TLAP to develop *Delivering Care and Support Planning Supporting Implementation of the Care Act 2014*.<sup>63</sup> NDTi's Community Led Support programme includes developing local area approaches to assessment, care and support planning and review. The emphasis is on enabling creative, outcome-focused conversations and plans, which result in strengths-based, personalised, local support.

After finding that just 12% of people with a musculoskeletal condition currently have a care and support plan, Arthritis Research UK's Care Planning and Musculoskeletal Health report<sup>64</sup> calls for commissioners and systems to ensure that care planning is available to people with musculoskeletal conditions. The report includes calls for care planning to be designed to include those with musculoskeletal conditions and to identify and address musculoskeletal needs in patients with any long-term condition; and professional bodies to ensure that the continued training of healthcare professionals involved in care planning includes core musculoskeletal skills.

Compassion in Dying have produced the policy report *Plan Well, Die Well*<sup>65</sup> which makes the case for Advance Care Planning and calls on commissioners and service providers to address the barriers to enabling patient-centred care at the end of life.

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## CONCLUSION

By sharing examples of the contributions of VCSE organisations throughout the care and support planning process, this paper offers a 'typology' of potential roles for the VCSE sector.

We hope that by demonstrating how VCSE organisations can meaningfully contribute to the care and support planning process, and offering practical examples of the diverse ways in which this is already happening, we will stimulate important discussion around how we can harness the skills, experience and reach of the VCSE sector to work towards ensuring that all people living with long term health needs and disabilities are able to benefit from this approach.

**Please do join the conversation:**

Share your comments, suggestions and contributions about the role of the VCSE sector in care and support planning on social media using #PlanForLife

Contribute your own examples of good or promising practice, or experience of care and support planning by contacting [natalie.koussa@nationalvoices.org.uk](mailto:natalie.koussa@nationalvoices.org.uk)

If you are a VCSE organisation interested in joining Wellbeing Our Way's care and support planning community of practice, please contact [natalie.koussa@nationalvoices.org.uk](mailto:natalie.koussa@nationalvoices.org.uk).

The community of practice is a small group of voluntary, community and social enterprise (VCSE) organisations who aim to develop care and support planning within their own organisations, and make a contribution to the development of care and support planning across the VCSE sector more widely. The community led the development of this discussion paper.

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### **THE CARE ACT**

The Care Act 2014 gives local authorities a new legal responsibility to provide a care and support plan (or a support plan in the case of a carer). It specifies that the person must be involved in developing their own plan and that the local authority must do everything it 'reasonably' can to agree the plan with them. The Act also provides a legal entitlement to a personal budget, which is an important part of the care and support plan, except in specific circumstances.

### **INTEGRATED PERSONAL COMMISSIONING**

Integrated Personal Commissioning (IPC) is an NHS initiative which aims to develop integration and personalisation for particular population groups - children and young people with complex needs; people with multiple long-term conditions, particularly older people with frailty; people with learning disabilities with high support needs; and people with significant mental health needs.

A core element of IPC is its care model which combines personalised care and support planning with an optional personal health and social care budget. Importantly, the proposed care model will include independent advocacy, peer support and brokerage.

### **REALISING THE VALUE**

The NHS Five Year Forward View published in October 2014, sets out how the health service needs to change, arguing for a new relationship with patients and communities. It makes a specific commitment to do more to support people with long term conditions to manage their own health. With the help of voluntary sector partners, it signals the need for significant investment in evidence-based 'more than medicine' approaches such as group based self-management education courses for people with specific conditions, as well as encouraging independent peer-to-peer communities to emerge.

To support this commitment, NHS England is funding the Realising the Value Programme which will help strengthen the case for change, identify a set of evidence-based approaches and develop tools to support their wider implementation across the NHS and local communities

Realising the Value is led by Nesta and the Health Foundation, working in partnership with Voluntary Voices (made up of National Voices, Regional Voices, NAVCA and Volunteering Matters), the Institute of Health and Society at Newcastle University and the Behavioural Insights Team.

### **THE COALITION FOR COLLABORATIVE CARE**

National Voices, alongside NHS England, is a founder member of the Coalition for Collaborative Care. The Coalition aims to work with major initiatives and programmes to demonstrate how person-centred, collaborative care can be achieved and 'create the conditions' to allow person-centred care to flourish. This will include using the evidence and building the case for change needed to influence and support systems and practice, working with leaders at all levels to develop new workforce approaches and strategies,

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and identifying and helping to pull the system and financial levers that will remove barriers and incentivise the changes we seek.

## **THE FIVE YEAR FORWARD VIEW – PEOPLE AND COMMUNITIES BOARD**

Chapter 2 of the Five Year Forward View looks to a future of a health system with a new relationship with patients and communities and sets out a series of commitments in relation to empowering people, supporting carers, promoting volunteering, and engaging the voluntary sector and communities.

The People and Communities Board exists to:

- champion the Chapter 2 vision and commitments and more broadly ensure that person-centred care and community-centred services are embedded in the Five Year Forward View programme
- harness the expertise of patients, service-users, engaged citizens, the voluntary sector, and other stakeholders, providing a support and challenge function in relation to the delivery of the commitments across the whole of the Five Year Forward View, including those that relate to prevention and new models of care.

Further information about the People and Communities Board, including its membership and meeting minutes can be found at [www.nationalvoices.org.uk/FYFV](http://www.nationalvoices.org.uk/FYFV).

## **JOINT REVIEW OF INVESTMENT IN VOLUNTARY, COMMUNITY AND SOCIAL ENTERPRISE ORGANISATIONS IN HEALTH AND CARE SECTOR**

The Department of Health (DH), Public Health England (PHE), NHS England and representatives of the VCSE sector are working together to review how government invests in the VCSE sector in health and care.

The interim review states that:

*it is being increasingly recognised that voluntary and community sector (VCS) inputs will form a significant part of future care provision, for example through social prescribing, community development approaches to health, the 'more than medicine' elements of the House of Care, and support for people to understand and use personal budgets.*

Please see the interim report<sup>66</sup> for further detail.

## **PERSONALISED CARE AND SUPPORT PLANNING HANDBOOK: THE JOURNEY TO PERSON-CENTRED CARE**

This handbook<sup>67</sup> provides an introduction to personalised care and support planning. It contains and links to practical guidance, case studies and theory on how to introduce personalised care and support planning. The document aims to support business planning and to encourage reflection and innovation for local approaches to implementation.

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# National Voices

People shaping health and social care

National Voices is the coalition of health and social care charities in England.

We want health and care systems which are person centred. This means that care is coordinated, people are in control of decisions about their health and care and everyone has fair access to care and support.

We have more than 140 charity members and 20 professional and associate members. Our membership covers a diverse range of conditions and communities and connects with the experiences of millions of people.

National Voices' Wellbeing Our Way programme is about enabling people to manage their health in ways which matter to them. We work through community and voluntary organisations. Wellbeing our Way is supported by The Health Foundation, an independent charity committed to bringing about better health and health care for people in the UK.

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**WE ARE  
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CANCER SUPPORT

