

## **Dementia Post Diagnostic Support Services**

# **Essential 5 criteria bundle and implementation guide on personalised planning for future care**

### **Background**

The Essential 5 bundle and the associated elements have been developed in collaboration with a number of partners around Scotland from November 2014 to date. Led by the national Focus on Dementia team, partners have included Alzheimer Scotland, National Dementia Carers Action Network, Scottish Dementia Working Group, academic colleagues, staff working in health and social care partnerships including link workers and service managers, colleagues from NHS Education for Scotland, Healthcare Improvement Scotland and Scottish Social Services Council.

The Essential 5 bundle has been tested in practice in 4 health and social care partnership areas including Glasgow, West Lothian, Midlothian and Borders.

This final Essential 5 bundle is now being made available for implementation by all agencies, integrated bodies and partnerships with a responsibility for delivering post diagnostic support (PDS) services in Scotland. This Essential 5 bundle has potential to be used in a variety of settings across health and social care.

This work supports improvements in the quality of post-diagnostic support and will enable practical implementation for meeting the HEAT target by March 2016.

### **Purpose of the bundle and this implementation guide**

Personal outcome approaches and personalised planning mean that support needs to be centred around what matters most to the person and their carers. This involves engagement with the individual and the carer as equal partners about what is important to them in their lives, good quality recording of this and then using this information for decision making and quality improvement. The bundle clarifies the expected minimum level of personalised planning for the future care of people with dementia, supported by the designated PDS link worker and involving carers, families and others close to the person.

It is acknowledged that the practice of planning for future care is currently variable across Scotland and this bundle will contribute to a continuous improvement approach to be taken to achieve reliability with each of the elements of the five criteria within a reasonable timescale.

Application of the essential criteria will support high quality personal planning and a consistent approach will be applied whatever model of post diagnostic support is in place. We acknowledge that the bundle alone will not provide consistent high quality personalised outcome planning. Skilled high quality person centred conversations with the person with dementia, their families and carers will be key.

This bundle and implementation guide is about the approach, content and outcomes expected from such planning. It is NOT about the form or structure of the plan itself.

The implementation guide explains more about what is expected and what is meant by some of the terms used.

## **Who it is for**

Both the bundle and implementation guide should be available for use by the practitioner/link worker working on the personal plan with the person with dementia, their carers and others close to them. Other colleagues responsible for delivering post diagnostic services whether in health, social care (including housing), the voluntary and independent sectors may have a contribution to make. However ownership of the plan rests with the person with dementia, or carers where appropriate.

## **Why it has been developed**

To improve the quality of personalised outcome planning to ensure that the needs and aspirations of people with dementia are explicitly understood, documented and supported, during and beyond the period of post diagnostic support.

## **How to apply it in practice**

The Implementation Guide is set out below.

The Essential 5 bundle on personalised planning for future care is set out in the associated form.

## **Principles and values**

In line with Scotland's Dementia Strategy, this work supports people with dementia, their carers and families. The work promotes well-being and quality of life through identifying what is important to the person with dementia and their carer, protects their rights and respects their humanity.

## Implementation Guide

### Applying the Bundle

The 'bundle' approach provides a structured way of improving the process around personalised planning to improve quality and reduce variation. The bundle ties the changes together into a package that people know must be followed for every person every time. The bundle is easy to measure and relies on all elements being met in order to achieve overall compliance.

By taking a retrospective sample of personalised outcome plans and reviewing these against the bundle, practitioners will be able to identify elements which are missing from the plan in order to inform improvements. By asking the person with dementia (or their carer where appropriate) you will be able to evidence whether the person feels that all key elements have been captured in the plan.

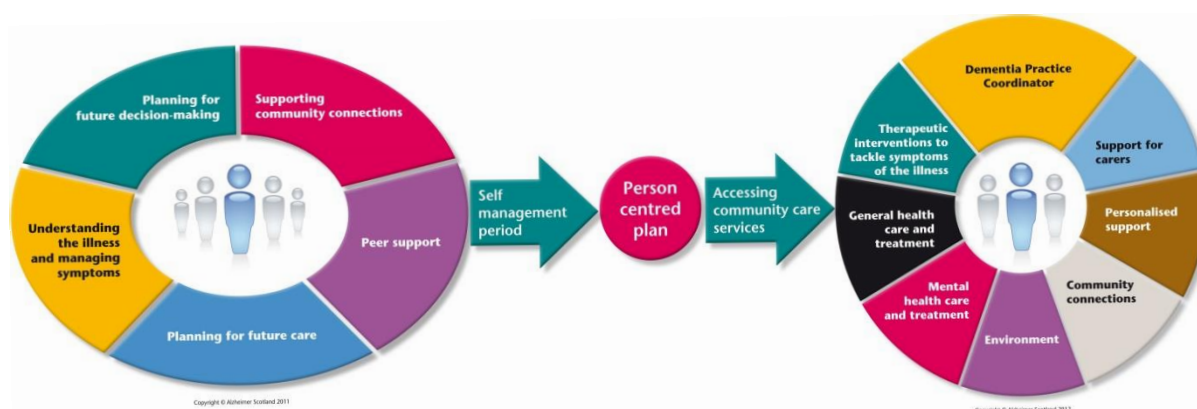
This is about the practicalities of improving the quality of personalised outcome planning and achieving a minimum level based on each of the elements of the 5 criteria of the bundle.

The personal plan itself, whatever form that takes, should be accompanied by progress/development notes that sit alongside the plan but are not necessarily an integral part of the plan per se. To evidence a person-centred approach, the progress notes may include, for example:

- The dates when the link worker met with the person.
- Recording of any non-decision making so that any apparent lack of information in the personal plan is not viewed as an oversight.

However, these progress/development notes would not need to be included in the personalised plan itself.

### The relationship between the 5 and 8 Pillar models and where the person centred plan sits:



### Transition Points

Transition points occur in the care journey where there is a change in the level and nature of care/support required. This can include, for example:

- Where care/support may appropriately change to reflect the evolving needs of the individual in line with the plan and current assessment of needs.
- Where the care setting may change temporarily (for example a necessary admission for acute care treatment) or permanently (for example to a care home).

Within the context of personalised planning it is important to consider that transition points are not restricted to the period of post diagnostic support – they can occur at any time in the life of the person with dementia.

## **Carers**

The involvement of carers, family members and others close to the person is key to the formulation of the plan and usually to its delivery. This should also include consideration of the carer's own personal position, what they are able and prepared to contribute and what supports they need themselves. It is acknowledged that whilst there are many carers fully committed to delivering support there are some who are less well placed to do so. The involvement of the carer is particularly required where the person themselves may lack capacity to create and update their own plan.

## **Who holds the plan?**

The plan itself, whatever form it takes, needs to be available to all of those who have a part to play in ensuring that it is applied in practice. That means across the whole "system" including the home setting, primary and community care settings, acute care, and in care home or longer term hospital settings. The person with dementia whose plan it is may have a clear view as to who they want to "hold" the plan, as might the family carer. The necessity is to ensure that it is readily available both for practical application of the person's expressed wishes and for pro-active updating. Ultimately the decision on who the plan is shared with lies with the person with dementia or carer as appropriate.

## **Case study**

Some personal plans in Glasgow City were reviewed against the Essential 5 Bundle. By going through the elements of the bundle systematically, we looked for written evidence of the key themes.

We found the bundle was clear and easy to use. Some of the evidence we required was in the plan itself, but was also found in separate link worker progress notes, which described PDS visits and discussions with the person with dementia and carers. These often captured the emerging issues which were important to the person and those that were not. Some of this information may not have been in the plan itself, but it helped evidence the process of personal plan development during the period of PDS.

The bundle helped to show where we were able to evidence aspects of good personal planning, and also where we needed to do more work. For example, we found that we needed to be clearer about who would review the plan once in place and who it would be shared with and that we needed improved evidence of using personal outcomes. We were able to show that we were considering personal resilience and that the person was often at the centre of the plan.

The Essential 5 bundle will help us consistently audit our personal plans, and help both improve the process of personal planning and how we record it in order to show evidence.

Further information and resources on personal outcome planning:

### **Promoting excellence in supporting people through a diagnosis of dementia**

NHS Education for Scotland (NES) and the Scottish Social Services Council (SSSC) have developed this learning resource to help health and social services staff further develop their ability to support people with dementia and their families before, during and after receiving a diagnosis of dementia. It forms part of a broader range of learning resources produced by NHS Education for Scotland (NES) and the Scottish Social Services Council (SSSC) to support implementation of the 'Promoting Excellence' framework (Scottish Government, 2011a) and the 'Standards of Care for Dementia in Scotland' (Scottish Government, 2011b).

The knowledge and skills described in the resource reflect the 'Enhanced' level on the 'Promoting Excellence' framework and focus on the key knowledge and skills required to use a personal outcomes-focused approach to support people with dementia and their families through a diagnosis of dementia. The learning resource highlights best practice in supporting the person and their family through the process of assessment, in conveying a diagnosis of dementia, in support planning and in working alongside them to support them to remain as independent as possible following a diagnosis. The resource can be accessed via the NES website:

[http://www.nes.scot.nhs.uk/media/2614737/supporting\\_people\\_through\\_a\\_diagnosis\\_of\\_dementia.pdf](http://www.nes.scot.nhs.uk/media/2614737/supporting_people_through_a_diagnosis_of_dementia.pdf)

Scottish Government (2011a) Promoting Excellence: A framework for all health and social services staff working with people with dementia, their families and carers

<http://www.gov.scot/Publications/2011/05/31085332/0>

**Scottish Government (2011b) Standards of Care for Dementia in Scotland: Action to support the change programme, Scotland's National Dementia Strategy**

<http://www.gov.scot/Publications/2011/05/31085414/0>

**Meaningful and Measurable** – a one year Collaborative Action Research project funded by the Economic and Social Research Council (ESRC). The project brings together 3 academic organisations, 8 practice partners and 4 national stakeholder organisations with a shared interest: adopting a focus on personal outcomes in health and social care settings. More information is available at: [meaningfulandmeasurable.wordpress.com](http://meaningfulandmeasurable.wordpress.com)

**Talking Points: personal outcomes approach - practical guide** – developed by the Joint Improvement Team to support the continued implementation of the Talking Points: Personal Outcomes Approach. While the Talking Points approach was developed primarily with reference to health and social care, it is increasingly evident that many of the principles and practice issues are relevant to outcomes based working across service sectors. The guide draws together evidence from research and practice and presents an overview of the key messages and learning from that work. The guide can be found at: <http://ix.iriss.org.uk/content/talking-points-personal-outcomes-approach-practical-guide>