

NHS England Dementia: Good Personalised Care and Support Planning

**Information for primary care
providers and commissioners**



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Document Status

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Dementia: Good Personalised Care and Support Planning

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Promoting equality and addressing health inequalities are at the heart of NHS England's values. Throughout the development of the policies and processes cited in this document, we have:

Given due regard to the need to eliminate discrimination, harassment and victimisation, to advance equality of opportunity, and to foster good relations between people who share a relevant protected characteristic (as cited under the Equality Act 2010) and those who do not share it; and

Given regard to the need to reduce inequalities between patients in access to, and outcomes from healthcare services and to ensure services are provided in an integrated way where this might reduce health inequalities.

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Dementia Good Personalised Care and Support Planning

1 Introduction

Personalised Care and Support planning (PCSP) planning is a priority for NHS England and plays a vital role in improving the quality of mental health and dementia services. NHS England is committed to:

- supporting the delivery of the recommendations in the '*Prime Minister's challenge on dementia 2020*' including improving the 'quality of post-diagnosis treatment and support for people with dementia and their carers'; and
- leading 'a step change in the NHS in preventing ill health and supporting people to live healthier lives', a key priority in the NHS England Mandate.

PCSP is a crucial element in delivering improved care for all people living with dementia, and supporting their families and carers. This has been brought into sharp focus through the CCG Improvement and Assessment Framework which includes indicators for dementia diagnosis and post diagnostic support.

This document has been developed with input from a diverse range of people living with dementia, their carers and health and social care professionals, to offer a quality assurance framework to enable more effective care planning, personalised and responsive to needs and preferences.

There is an urgent need to ensure every person who has dementia has an individual PCSP and to aim for, wherever possible, greater integration with support plans in other areas such as social services.

The information provided in this resource document highlights the key characteristics of a PCSP for dementia and is aimed at primary care and commissioners who provide PCSP reviews as part of the Quality Outcomes Framework (QOF) incentive scheme in primary care.

Improved personalised care and support planning in dementia services will be achieved by:

- supporting a standardised approach reducing unwarranted local variation in process or outcomes;
- promoting equality and tackling health inequalities;
- ensuring alignment with relevant cross condition care plans such as diabetes; and
- drawing on examples of good practice around the country.

This resource document covers:

- The components which constitute the **minimum information** to be included in a good care plan.
- Examples of dementia PCSPs that are **already being used** at a local level.

- Considerations for **computer systems** available in primary care to create a dementia care plan and make appropriate links to PCSPs for correlated conditions.

2 Components of Dementia Personalised Care and Support Planning: the fundamentals

2.1 Definition

2.1.1 Personalised Care and Support Plan

Essentially, the output of the personalised care and support planning process is a written plan which is clear, simple and precise, and explains what matters to the person, what care and support the person is having, contingency plans for the future, and arrangements for review. As a benchmark / point of reference, the NHS England [Summary Guide on personalised care and support planning](#)¹ indicates that personalised care and support planning is a series of facilitated conversations in which the person, or those who know them well, actively participates to explore the management of their health and well-being within the context of their whole life and family situation. The process recognises the person's skills and strengths, as well as their experiences and the things that matter the most to them. It addresses the things that aren't working in the person's life and identifies outcomes and actions to resolve these.

Personalised Care and Support Planning is one of the Long Term Plan metrics. The total number of new or reviewed plans within year, that meet the criteria below, will be counted.

A set of PCSP counting criteria have been created in partnership with commissioners, people with lived experience, stakeholders and professionals. The following criteria represent a basic level of provision of PCSP in a local health and care system, providing a foundation for further improvements:

1. People are central in developing an agreeing their PCSP including deciding who is involved in the process.
2. People have proactive personalised conversations which focus on what matters to them, paying attention to their needs and wider health and wellbeing.
3. People agree the health and wellbeing outcomes they want to achieve in partnerships with the relevant professionals.
4. Each person has a sharable PCSP which records what matters to them, their outcomes and how they will be achieved.
5. People are able to formally and informally review their PCSP.

¹ Integrated Personal Commissioning: Personalised Care and Support Planning: Summary Guide

2.1.2 Consideration should also be given to the accessibility of a patient's PCSP. It is recommended that:

- Services need to work with individuals to discuss and record information in a way that is accessible to the patient, using a language that is recognised. This could involve the use of advocacy services, interpretation and translation services, peer support, or the provision of information in alternative formats, such as easy-read, pictorial, or audio. Where individuals have a disability, impairment or sensory loss, NHS organisations are legally required to follow the [Accessible Information Standard](#)² and provide information that can be easily read or understood, and to support individuals in communicating with services.
- Services might wish to consider the use of tools such as the [Patient Activation Measure](#)³ or a Health Literacy Questionnaire, to help identify individuals with lower levels of health literacy, or knowledge, skills and confidence to manage their condition. They can then offer additional support to help people contribute to the care planning discussion and to record the care plan in a way that will best meet their needs.
- Personalised care and support planning should take account of a patient's needs and wishes, taking into consideration their capacity to make decisions and the need to act in accordance with the [Mental Capacity Act Code of Practice](#)⁴. Staff should be trained in the requirements of the Code of Practice.

2.2 When should personalised care and support planning take place?

- Personalised care and support planning should take place as soon as possible after diagnosis (irrespective of where that happens) and:
 - **the frequency of reviews should be** responsive to the needs of all individuals diagnosed with dementia. It is important that a review date is set when the initial care plan is agreed. As a minimum, the plan should be reviewed annually (any reviews should always be with the person living with dementia and their family/ carers to reflect changes in needs and wishes;
 - **personalisation should be** incorporated in the system used to support the plan, in order to enable an appropriate level of consideration for those who have additional risk factors including, for example a history of wandering, carer stress, or multiple long term conditions, so that they can easily be identified for early review; and

² <https://www.england.nhs.uk/ourwork/accessibleinfo/>

³ <https://www.england.nhs.uk/ourwork/patient-participation/self-care/patient-activation/pa-faqs/#11>

⁴ https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/497253/Mental-capacity-act-code-of-practice.pdf

- **due care and attention should be** given to [the Mental Capacity Act Code of Practice](#)⁵.
- Outcomes of a PCSP are a key measure of its efficacy and assessing this is important. The following three outcome tools are recommended for routine use in memory assessment services:
 - Health of Nations Outcome Scale-65 (HoNOS-65);
 - Friends and Family Test (FFT); and
 - Patient Experience Questionnaire (MOPE-PEQ).

2.3 What support is needed to ensure personalised care and support planning is undertaken consistently, reliably and continues to happen?

- **Consistency:** the minimum requirements in dementia personalised care and support planning are covered in '[3.Core Elements of a good care plan](#)' and '[Table 1: Examples of good practice](#)' below. These examples indicate good practice but need to be assessed against local context and should only be adopted if they are likely to improve value to services and people living with dementia or their carers.
- **Reliability:** all staff completing PCSPs need to be competent and trained. Training for staff in facilitating personalised care and support planning is important, particularly regarding the 'what matters conversation / discussion'. A combination of e-learning and role play / simulations are likely to be most effective. It is recommended that this covers:
 - Motivational interviewing;
 - Supporting people with low levels of knowledge, skills and confidence to manage their condition; low levels of health literacy; reduced capacity to make decisions; or specific communication needs;
 - Asking open questions;
 - Encouraging full answers from the person diagnosed with dementia using an impartial approach; and
 - Ensuring that the care plan is written from a person-centred perspective, and includes the views and needs of carers.
- **Continuity:** to ensure that the practice of care planning for dementia is fully embedded and maintained, it should be monitored through the Information Assurance Contract (IAC) for completion rates and quality (i.e. did it happen and did it help?).

⁵ https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/497253/Mental-capacity-act-code-of-practice.pdf

2.4 What should be the process for personalised dementia care and support planning?

- **Who?:** Any member of primary care staff with the necessary competencies should complete a PCSP with the person living with dementia, and their carer if the person gives consent or if they lack capacity, in accordance with the [Mental Capacity Act Code of Practice](#). Dementia Advisors are ideally placed to establish the initial development of a personalised care plan, which could then be augmented by GPs. Also, if appropriate training can be provided, other members of the practice team could progress the initial formulation. The PCSP should be personalised, unique to the individual and owned by them. It may be that the person or their family may want to develop the plan in partnership with relevant professionals and this should be supported.
- **How?:** The preliminary personalised care and support planning conversation with the person living with dementia (and their carer if appropriate) should begin with asking what is important to them, with an initial focus on what their main concerns and priorities are regarding the present time and the future outcomes.
- **Content:** A dementia PCSP should be empowering / proactive, written in 'Dementia friendly' language and fully linked in to all aspects of the individual's healthcare record, rather than 'standalone'. A full personalised care and support plan should have core information on demographics, carer details, information sharing agreements, admission avoidance, details of other correlated conditions and medication.
- **Crucial service links/ continuity of care:** Information from other agencies, for example Memory Services, Dementia Advisors Social Services and care homes, should be incorporated into the personalised care and support planning process through multidisciplinary team working and be reflected in the care plan. An example of a system that allows relevant information from the PCSPs of people with Long Term Conditions in Primary Care to be shared with the ambulance service (using the IBIS system) and Community Care IC24 is given in Table 2 below.

3 Core elements of a personalised care and support plan

This section should give a detailed overview of the roles and responsibilities of key staff, departments and committees for the implementation of the procedural document.

As previously referenced, personalised care and support plans will be one of the metrics collected as part of the implementation of the Long Term Plan. In order to be counted a PCSP must meet all of the criteria below:

People are central in developing and agreeing their personalised care and support plan including deciding who is involved in the process

The personalised care and support planning process should empower the person as an active participant rather than a passive recipient. This means they or their family, will have a say over who is involved. It should value their expertise, skills, strengths and experience with equal importance. The process means that the person has been well prepared for the planning, so they know what to expect and including being given information and advice which meets their individual information needs.

People have proactive, personalised conversations which focus on what matters to them, paying attention to their needs and wider health & wellbeing

The person is seen as a whole person in the context of their whole life. The planning conversation starts by exploring what matters to the person, the things that make for a good life for them, before exploring the support they need to manage their condition. The person is listened to and understood in a way that builds trusting and effective relationships.

People agree the health and wellbeing outcomes they want to achieve, in partnership with the relevant professionals

The person develops health and wellbeing outcomes, in partnership with relevant professionals, that are based on things they wish to change or achieve, rather than just on what professionals feel they should achieve. They are written from a personal perspective, that reflects the person, rather than in service language.

Each person has a personalised care and support plan which records what matters to them, their outcomes and how they will be achieved – in a digital format where possible.

Plans can be recorded in a variety of formats, paper, electronic systems and digital formats that the person can edit. Whatever the format, the plan must contain a record of what matters to the person as well as the support they need to manage their condition. This can be as simple as a one-page summary or profile of this information, but it must be there to be counted. The plan must also include the agreed outcomes the person wishes to achieve and an action plan showing how they will be supported to achieve these. Where appropriate, the plan should include information on contingency and risk and if the person has a personal, personal health or integrated budget then it should have a budget sheet showing how the budget will be spent.

People have the opportunity to formally and informally review their care plan.

A personalised care and support plan should be a living, not static document. Although there is a clear statutory requirement to annually review the plan the person should have the opportunity to informally review their plan on an ongoing basis. They

should also be able to request a more formal review if there is a change to their situation.

A dementia personalised care and support plan should cover [D.E.M.E.N.T.I.A.](#):

D

Diagnosis review

Check the diagnosis given is correct and confirm the patient's (and family and carer's) understanding of it.

E

Effective support for carers review

- Carer information: When a person receiving a PCSP has a carer identified it is important that their carer is made aware of their right to a carer's assessment. Who is/are the carer(s) of the person living with dementia? Who are the next of kin?, Has the carer had a carers assessment? If not, how can they access this? Does the carer need a care plan to address his or her needs?
- Information provision: has the person living with dementia and their carer got all the necessary information they need to make decisions about their care? (Signpost to [Dementia Guide](#), [Dementia Connect](#), National Dementia Helpline (0300 222 1122) as appropriate)
- Information sharing: who is the person living with dementia willing for information to be shared with? Specify who this includes for example relatives, friends, health and social care professionals?
- Legal/financial: Advanced decisions Lasting Power of Attorney (LPA), capacity issues in accordance with the Mental Capacity Act including liaison [with Best Interest assessors regarding DoLS](#), personal budgets, driving and DVLA notification.
- Research: has the person living with dementia and their carer(s) been offered the chance/support to register with 'Join Dementia Research' (JDR) and /or participate in local research projects? Have the benefits of research been explained?

M

Medication review

- Physical health: this should include
 - medication reviews, to reduce poly pharmacy, minimise use of drugs which impair cognition, and stop any unnecessary medications;
 - specialist reviews, nutrition and hydration, detailing the persons preferences to work with as a positive, that is, encouragement to try new things;
 - exercise and comorbidities, including a holistic view of the person to indicate any other long term conditions they have, plus other health needs and preferences for example dentistry, podiatry, optometry, continence

care, dietician, speech and language therapy, physiotherapy and occupational therapy.

- Mental health: this should include psychiatric meds, cognitive stimulation therapy and treatment of depression and or anxiety as appropriate.

E

Evaluate risk

- Additional risk factors: should be considered including safeguarding issues, and for example, carer stress, or a high number of long-term conditions, so that they can easily be identified for early review. Example prompt questions to ascertain carer stress or BPSD that non specialist staff might be uncomfortable enquiring about (for example sexual disinhibition or psychosis) could be:
 - For the person diagnosed with dementia - Does your imagination ever play tricks on you?
 - For the carer - Does the person you are caring for do or say anything to make you feel uncomfortable?

N

New symptoms inquiry

Following reviews: any new symptoms should be investigated and treated or managed as appropriate.

T

Treatments and support

Post-Diagnostic Support: what are the appropriate approaches and interventions? This should include spiritual, cultural and emotional care as well as compensatory, restorative / rehabilitative and palliative approaches, and support for self-management, to maximise the person's abilities rather than any deficiencies. Interventions might embrace an environmental needs assessment, assistive technology, talking therapies for example cognitive behavioural therapy, cognitive stimulation therapy, complementary and alternative therapies, and pharmacological management.

I

Individuality

There will always be things unique to the person and their family - Living well: What are the interests / hobbies / social functioning / ADLs of the person living with dementia, and how can they be maintained?

Individuals need to be empowered to manage their health and wellbeing with support where needed. How will the person will manage their condition and what support do they need for self-management? What appropriate goals or actions could be discussed and agreed?

A

Advance care planning

Future care planning: wishes regarding what happens if or when capacity is impaired, wishes regarding care and treatment in the later stages of dementia, including preferred place of death, and whether the patient wishes to discuss an advance care

plan for end of life issues. For guidance, refer to [My Future Wishes: Advance Care Planning \(ACP\) for people with dementia in all care settings](#).

4 Exemplar personalised care and support plans

An exemplar PCSP should take into account the five steps of the well pathway for dementia, wherever possible and appropriate. These include preventing well (when prevention includes secondary and tertiary prevention), diagnosing well, supporting well, living well and dying well. For more information please refer to: [NHS England Transformation Framework – the well pathway for dementia](#).

A dementia personalised care and support plan should also be:

- set out from the perspective of the person living with dementia;
- compatible with prevailing information systems such as EMIS and include clinical observations, assessments, plans and reviews, administrative notes, follow up dates, test recordings, principles relevant for LES, CQUIN, well pathway and a carer review;
- inclusive of an annual review (it is important that a review date is set when the initial care plan is agreed); and
- easily implemented and aligned to the fulfilment of the QOF (please refer to Table 1, example No.8 for a model of QoF annual review templates available for EMIS Web and SystemOne practices).

Table 1: Examples of good practice		
No.	Example	Document/ Link
1	A person-centred care plan - Dr Jennifer Bute, retired GP, expert by experience and founder of a resource website for people living with dementia.	Care plan – (person-centred)
2	A care plan: system compatibility and configuration - Dr Jill Rasmussen – Royal College of General Practitioners Clinical Lead for Dementia and Strategic Clinical Network South East Clinical Lead for dementia. Note: this resource was developed by Guildford and Waverley CCG	A care plan: system compatibility and configuration
3	A dementia care plan annual review template - Dr Emma Tiffin, GP, Strategic Adult Mental Health Clinical Lead, Cambridgeshire and Peterborough CCG, Interim Older Peoples Mental Health Clinical Lead, Cambridgeshire and Peterborough CCG	A dementia care plan annual review template
4	A care plan: implementation and alignment with overarching requirements - Dr Sara Humphrey, GP Bradford and Airedale and GP advisor to the Yorkshire and Humber Dementia Strategic Clinical Network.	A care plan: implementation and alignment

Table 1: Examples of good practice		
No.	Example	Document/ Link
	Note: further information on the care plan can be obtained from nicola.phillis@nhs.net , penny.kirk@nhs.net or colinsloane@nhs.net . Further information on the use of the 'What could really make a difference' tool can be obtained from Year of Care partnerships www.yearofcare.co.uk	
5	A framework for annual review - Dr Jonathan Kaye, GP Kingsway medical practice additional example framework for an annual review	A framework for annual review
6	An example of a care planning template (developed by NHS Year of Care) that can be uploaded to EMIS/Vision - Thames Valley Area Team. In Thames Valley this has been implemented widely for Diabetes and COPD in primary care and is being extended out to Dementia. The template is intended to be used for any Long Term Condition and is not disease specific.	An example of a care planning template (developed by NHS Year of Care)
7	An example of a Dementia Care Plan Annual review template - NHS Bolton	Dementia Care Plan Annual review template
8	An example of QOF annual review templates available for EMIS Web and SystmOne practices - Yorkshire and Humber	Dementia QOF toolkit for SystmOne Practices
9	<p>Examples of Advance Care Planning:</p> <p>A/ An example of a county-wide Advance Care Plan developed in Gloucestershire that has won an award from the BMA.</p> <p>B/ Three examples of Advance Care Planning documentation from Humber, which are sent out as soon as any patient is placed on the Palliative Care register in the GP practices. Humber is currently doing a pilot with Dementia Nurses in Goole where they are using the documentation and it has been well received by families and patients.</p> <p>Please note: 'Advanced' should read 'Advance' throughout.</p>	<p>Gloucestershire – county-wide Advance Care plan</p> <p>Humber NHS Foundation Trust (My Advance Care Plan)</p> <p>Humber NHS Foundation Trust (Caring for me ACP)</p> <p>Humber NHS Foundation Trust (Caring for me - info for patients & families & carers).</p>

Table 1: Examples of good practice		
No.	Example	Document/ Link
	C/ Two examples of Advance Care Planning documentation from the London Region	East London NHS Foundation Trust ACP South London and Maudsley Trust- Preferred priorities of care Plus reference material for Preferred priorities

5 Implementation: practicalities

5.1 Electronic Personalised Care and Support Plans

- Technology requirements – PCSPs should be:
 - completed in primary care to meet the DEM004 QoF requirement;
 - linked to GP records systems (SystemOne EMIS and others);
 - equipped for the auto-population of fields wherever possible, for example a ‘Dementia specific’ area should pull data through, such as READ Codes, medication and carer details from the core section. A locally modifiable code light basic minimum standard template for EMIS and System One would be ideal; and
 - for patients in the late stages dementia, the PCSPs could be considered for inclusion on the Electronic Palliative Care Co-ordination System.

It is important to note that completion of a dementia personalised care and support plan in digital format or on a hard copy is a matter of preference. Both sources of information are equally valid, as long as the completed hard copy is legible, scanned and tagged/ coded/ saved appropriately on the GP IT system.

- What is needed in the future? - Considerations include:
 - an IT- system that can share care plans with all agencies (with person’s consent). For example, secondary care and social services;
 - patient access to care plans online so that they can alter/check/revise it as appropriate; and
 - development of easy read versions for patients and carers with information relevant to them.

5.2 Table 2: Examples of correlated condition care plans and resources to inspire primary care thinking for dementia	
Origin	Publication
NHS England and the Coalition for Collaborative Care - Personalised Care Planning	<p>NHS England and the Coalition for Collaborative Care have published:</p> <ul style="list-style-type: none"> • <i>'Personalised care and support planning handbook: The journey to person-centred care'</i> comprising: <ul style="list-style-type: none"> ○ An executive summary; ○ *Core information on personalised care and support planning; ○ Information for commissioners; and ○ Practical delivery guidance. • <i>* 'MDT Development - Working toward an effective multidisciplinary/multiagency team'</i> <p>The aim of these publications is to help those with key local responsibilities for the future of the health service to respond to these expectations in respect of people with long term conditions – using the approach of personalised care and support planning.</p> <p>They draw on the latest research, best practice and case studies to show how this can be done.</p>
Bolton Council – Bolton Clinical Commissioning Group	A staying well toolkit to support a person with dementia in Self-management with or without domiciliary care or carer support.
NHS England developed a dementia pharmacy framework (Dr Jane Brown)	Seven Steps to becoming a Dementia Friendly Pharmacy Practice
Wessex Academic Health Science Network	A brochure detailing how to make a general practice surgery dementia friendly . In addition, Wessex AHSN has also provided an example check list for required actions.
South East Coast Ambulance Trust – NHS Foundation Trust	East Kent there is a project allowing relevant information from the Care plans of people with LT conditions in Primary Care to be shared with the ambulance service (using the IBIS system) and Community Care IC24.
Resources for diabetes care planning from Diabetes UK	https://www.diabetes.org.uk/Professionals/Resources/shared-practice/Care-planning/

5.3 Table 3: Advice for Commissioners	
Origin	Publication
London Clinical networks	London Clinical Networks published ' Guidance for commissioners on dementia post diagnostic support planning ' to support commissioners and providers of dementia care in meeting NICE Dementia Quality Standard on Dementia QS1

5.4 Table 4: Post Diagnostic Provision	
Origin	Publication
NHS England North	NHS England North have published ' Evidently Better Dementia ' to support commissioners with an overview of post-diagnostic support for people with dementia and their carers including examples of good practice, resources to support local organisations and sources of further information.
London Dementia Strategic Clinical Network	London Dementia Strategic Clinical Network (Living Well with Dementia working group) published, Immediate post diagnosis support guidelines – Living well with Dementia to support professionals working with people with dementia in health and social care settings; however it might also be a valuable resource for commissioners.
Alzheimer's Society	Post diagnostic support: ' Dementia Advisers: A cost effective approach to delivering integrated dementia care '