**End of Life Educational Package 4 - Personalised Care and Support Planning (PCSP)**

**Facilitator guidance notes**

**Lesson 1**

**Aim**: To demonstrate clarity about what Personalised Care and Support Plan (PCSP) is, and is not, and how this fits with other palliative and end of life care-related planning tools, e.g. ReSPECT, Advance Care Planning (ACP), etc.

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| **Time** | **Content** | **Teaching Methods** | **Resources** | **Slides & Facilitator notes** |
| 10 mins | Welcome & Introductions  Ground rules  Icebreaker | Trainer led presentation  Group participation | Ice breaker of your choice |  |
| 10mins  5 mins | What is Personalised Care and Support Planning?   * Personal story   What it is and what its not | Trainer led presentation  Video  Q & A/discussion | Slide set  Embedded video (or a co facilitator with lived experience) | Slide 3 - Personal Story  It is very powerful to start the workshop with a personal story presented in any format by somebody with lived experience. It is important that the focus of the story is on the difference a personalised approach has made to them. The film embedded in this slide is about Max. Max died from bowel cancer a number of years ago. In his working life he was part of an international community of people who used person centred approaches in his day to day work. As he neared the end of his life he was determined to show how important it is to take a personalised approach with people at the end of their lives. This film and others he made, are his legacy.  What it is and what it is not  Slide 5 Definition slide – this is the definition of personalised care and support planning used in Universal Personalised Care. Draw people to the two phrases that are highlighted as these are the key aspects of what we mean by personalised care and support planning. Move to next slide  Slide 6 Fundamentally its about… slide – explain this in more depth, the two key aspects about planning that is personalised rather than just good care planning, is that it starts with a different kind of conversation based on what matters to people; and recognising people as experts & equal partners in their own planning & care. |
| 15mins | What does good personalised care and support planning look like?   * Key features * Counting criteria   How does it link to other planning tools within EoL? | Trainer led presentation  Q & A/discussion | Slide set | Key features – explain NHSE wanted a clear way to define what a personalised care and support plan is, particularly for the purpose of counting. These key features have been developed by the Personalised Care strategic co-production group and therefore represent what good looks like for people. They are divided into 3 sections Perspective, process and plan:  Slide 7 - Perspective – this is a way of ‘seeing people’ and attitude towards them that is fundamental to good Personalised Care and Support Planning.  Slide 8 Process – what a good Personalised Care and Support Planning process will mean to the person.  Slide 9 Plan – this is what a good plan looks like.  Slide 10 LTP Metric slide – PCSP is one of 30 long term plan metrics. NHSE will be counting new completed PCSPs and existing PCSPs on review within the year.  Slide 11 5 Criteria Slide – These five criteria are a summary of the key features for PCSP and were developed to make it easier for people to see if the plans they are developing and therefore counting are of the right standard. Further technical guidance will be developed to support this.  Slides 12-17 How PCSP fits in (EoL planning tools) – PCSP is seen as an umbrella term, in groups identify existing care plans used within the locality and discuss if/ how they meet the five criteria. Slides 14-16 are aids. |

**Lesson 2**

**Aim**: To demonstrate skills and behaviours which enable the process of Personalised Care and Support Planning (PCSP) to be initiated and conducted in a way that is person-centred and supportive of the person.

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| **Time** | **Content** | **Teaching Methods** | **Resources** | **Slides & Facilitator notes** |
| 30mins  30mins  5mins  5mins  10mins  5mins  15mins  10mins  5mins | How do we find out what matters to the person at the end of their life?  Understanding and sorting important to/for  Six questions for the conversation  If I could I would  Decision Making Profile  Developing personalised outcomes and actions  Working/not working  Outcomes Process  Developing solutions  Other tools | Trainer led presentation and demonstration  Group work with a scenario for each tool | Slide set  Scenario to use for group work – printed copies | Presentation on Important to and Important for **– listen to the training webinar for further guidance on delivering this presentation.**  Slide 3 - In health and social care, you will often hear the phrase needs and wants or even needs vs wants. We know that as a system our ‘duty’ is to meet people’s needs and usually that is done very well. However, when we talk about wants, they are often seen as things that would be nice to have or not our responsibility. Another, more personalised why to view this would be to talk about what is important to people (wants) and what is important for people (needs). If you look at the quote above and apply that to thinking about the things that are important to people, they take on a lot more significance as they affect the quality of a person’s life. That is a lot stronger that a ‘nice to have’. Using this framework in planning is fundamental to personalised care and support planning. This is demonstrated more deeply over the next few slides.  Slide 4 - For many people using services are at any point in their life, our desire as a system to keep people as safe as possible and avoid risk, often dictates the support they get and therefore how they are living their life. Click the slide again to demonstrate a humorous illustration of this. You want to use a paddling pool and we get 4 men in hazmat suits involved. This is clearly not personalised.  Slide 5 - Then somebody comes along and tells us we have to be more personalised in our work, we have to give people choice and control. In giving people that control we often mistakenly this people will be irresponsible with that and end up in situations like the picture above. This is no more personalised that the first example.  Slide 6 - Personalisation brings this back into balance – we must strive to find a balance between what matters to people and how we support them with their clinical needs.  People are the experts in their own lives & we must know & pay attention to what matters to people & deliver support in the context of how people want to live  It’s the soul of our work & brings us back to a solid values base. ........we are talking about supporting an ordinary way of living your life...... and includes pleasure and purpose, and gets us moving away from those care plan tick boxes that often focus only on a person’s physical needs without also paying good attention to learning what matters to people.  Slide 7 & 8 – these two slides define the important to and for a little bit more  Slide 9 - Present an example of presenters important to/for. These tools are useful in all walks of life, you don’t have to be ill to use them. As a trainer, it is important to experience what it is like to think about your life in terms of what is important to you and what is important for you to pay attention to. You will need to develop your own example Important to/for and present it here, in place of this example.  Ask the group to think about their own important to/for  Slide 10&11 - A useful way of helping people to really understand this way of thinking is to get people to do some group work using a scenario. You will likely want to develop your own story that you are familiar with but you can use this one. Hand out printouts of this slide so people can see it. Read out the key parts of the story and then get people to identify and sort out what is important to and important for Madge. Take some feedback from them and discuss it as a large group before you show then the answers on the next slide.  Slide 12 – If you were to just ask people what matters to them, they would probably find it really difficult to answer that easily as it is a very big question. We have learnt that by breaking it down into six questions you will find out this information very simply and very quickly.  Slide 13 - **1. Who are the most important people in your life? How often do you see them and what do you like to do together?**  There are a couple of sub questions that it is also useful to ask here, like how often do you see people, what would you do with them?  Ask them to work in pairs or small groups and ask each other this question. Record their own answers. Give them 5 minutes to do this.  **2 & 3. What would make a good day for you and what would make a bad day?**  For the purpose of the exercise ask participants to think of 3 things that make it a good day and three things that make it a bad day at work. Once they have identified these you need to talk them through the following:   * Firstly, ask them to look through the lists and identify if anything on the lists tells them about something that is important to them about their work. They need to develop a sentence about this and record this under the important to section on their one page profile. * Secondly, they need to look at the bad day list and ask the question ‘Is there anything you need people to **know and/or do** to support you with this issue.   **4. What do you usually do during the week that you would miss if you didn’t do?**  You are looking for routines here and things that people do that they would miss if they didn’t do. These are usually things that are important to them and would be recorded in the **important to** section of their profile.  **5. What would you never leave home without in your bag or pockets?**  You are looking for information here about important possessions. People usually say their phone but ask them to think deeper than that. this would be recorded in the important to section.  **6. What would your family or best friend say they love and admire about you?**  Here you are looking for one word descriptions of people’s qualities and characteristics.  Dependent on the time you have you may just have to introduce the questions rather than demonstrate all of them.  Slide 14 - If I could I would – this is a really useful tool to help people think about things that they might like to do/achieve before they die. This can give people direction towards the end of their life and as services we need to ensure that the support and treatment we offer doesn’t get in the way of this where possible. This information should be part of any shared decision-making process around treatment.  Slide 15 - Key to a personalised approach is keeping people at the centre of any decision making around their life, treatment and support. The decision-making profile is a way of understanding how the person best processes and understand the information given to then. It enables us to support them really well in a shared decision-making situation  Developing personalised outcomes - Start with a brief discussion on what we mean by outcomes and in particular person-centred outcomes - **listen to the training webinar for further guidance on delivering this presentation.**  Slide 16 - Presentation on the mistakes we make with outcomes. Developing outcomes or goals with the person is a key part of the planning process. In personalised care and support planning outcomes need to be person centred based on a discussion about the things the person would like to change. There are three common mistake we make when developing outcomes or goals with people. This slide explains those. Often you will see an outcome written with the solution embedded in it, this is explained a bit more in the following slides. If the person is suggesting something like this then it is your job as a planner to explore with them what they actually want to achieve. If we don’t make outcomes specific enough we can’t measure them and it is then difficult to know if the support we offer is right. Lastly, we can often impose outcomes or goals on people that don’t relate to something that matters to them or something they need to do. We then wonder why people are no compliant with these.  Slide 17, 18 & 19 - Exploring the embedded solution problem a bit more. Explain that what we mean by a solution in this context and how that is different to an outcome. The questions are a way of helping you break through the idea of the solution and understand what it is the person wants to achieve. The next two slides explore this as an example  Slide 20 – The box on the left shows the key things that define what we mean by a personalised outcome and the box on the right has some examples of how you can write them differently to be more person centred.  Slide 21 - As part of the planning process we shouldn’t be developing outcomes with people until we have found out what matters to them and the things they may wish to achieve. **One page profiles will be explained further in lesson 4.**  Then we need to understand what their current situation is and what they may wish to change where possible. The working not working tool is a great way to do this.  Slide 22 & 23 - This is a great tool to help get an understanding of the person’s current situation. You can gather even richer information by asking other people involved in the person’s life what they think is working not working. Having identified a list of the things that are not working for the person it is then important to prioritise which ones the person might like to tackle first.  Slide 24- This is a simple four step process to help develop outcomes for the things that the person has said is not working for them right now. Take each not working issue separately and start by asking about the positive change the person would like to see in relation to this. Then make this specific and then ask if its achievable using the questions to further check.  Slides 25, 26 & 27 - Work through the example   1. Jane finds it hard to ask for help when she needs it 2. Reframed in a more positive way would be to ask for help when she needs it   3. Now we need to see if we can make this more specific. For Jane to feel comfortable asking for specific help when I need it and to not feel I am a burden to people. For example help with food shopping or cleaning the house. This is much more specific and therefore easier to measure whether it is achievable.  4. Does this sound like an achievable outcome?  Group work - Ask each table to think about a person that at least somebody on the table knows well enough to describe things that are not working for them. Using their example, get them to develop some outcomes to change the things that are not working.  Ask each table to share their example outcome  Give them feedback on how it could be improved if needed. Pay particular attention to the language used we are aiming for ordinary language and not service speak. Also watch out for embedded solutions or outcomes that are not specific enough.  Slide 28- Having developed the outcomes, now is the time to think about the solutions to achieving them. This is the HOW. As clinicians and practitioners we have a tendency to try to fix a situation and offer solutions that we think work best. These are often things that have to be paid for or are specialised services. Personalisation pushes to think beyond those boundaries and ask questions such as:  What can the person do for themselves to achieve this outcome?  Is there technology that might help?  What can family friends and neighbours do?  What local universal services are there that might help?  Slide 29 – Explain how Health Coaching, Shared Decision Making (SDM) and Personalised Care & Support Planning (PCSP) are interdependent.  Acknowledge that clinicians do already possess skills/ behaviours.  Resources are available which can assist clinicians in having more effective difficult conversations. Slides 30-34 provide key messages as well as where to go for further information.  Slide 30 - Emphasise that clinical judgement is key – although it is vital to have a 'what matter's to you' conversation it is just as vital to have a conversation about pain relief and how to manage exacerbations of pain.  Slide 35 – This is a theoretical example as to how Shared Decision Making and Health Coaching could be used to personalise care. Facilitators are encouraged to use their own experiences or draw on the experiences of those attending the training to iterate how the components are interdependent.  Slide 36 – People will not always have the capacity to partake in their care planning, signpost to the available e-learning. Facilitators may wish to explore this further with those attending training. |

**Lesson 3**

**Aim**: To demonstrate ability to support the involvement of those close to the patient in this process according to the patient’s wishes.

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| **Time** | **Content** | **Teaching Methods** | **Resources** | **Slides & Facilitator notes** |
| 10mins  10mins | Tools to support the involvement of family and friends   * Relationship maps * Decision making tools | Trainer led presentation and demonstration  Group work to think about how they may use these tools in practice  Facilitated discussion | Slide set  It may be useful to have copies of any local support leaflets | Slide 3 - A relationship map is a great way to think about all the people in a person’s life who might need to be involved in planning and decision making if they are unable to do that themselves. The people closest to the centre of the map in each area of the person’s life are the people who know them the best  Slide 4 – following on from using the decision making profile tool, we also have the decision making agreement. This is a way of capturing information on who will have the final say for specific decisions when the person may no longer have the capacity for decision making themselves.  The left-hand column is the place to record each specific decision the agreement covers. The middle column is a place to record who will help the person with the decision and how they will do that. This can be populated with information from the decision-making profile tool about how to support the person to understand information and make decisions. The right-hand column records who makes the final decision and may be different for each specific decision.  Slide 5-6 – Remind of the choice commitments and the ambitions framework.  Discuss:   * What does good care planning (with family/ carers) look like? How did it benefit the person? * When would it be inappropriate to include family/ carers in care planning conversations?   Slide 7 – Support is readily available to caregivers and the workforce. Facilitators may wish to map other carer support available locally.  Slide 8 – Iterate that support may be needed during bereavement (as well as pre-bereavement; last year, months, days). |

**Lesson 4**

**Aim**: To consider practice processes in terms of documenting PCSP, sharing the content with wider members of the team within and beyond practice, reviewing PCSP at trigger points (e.g. recent discharge following acute admission) or whenever the patient wishes to do so.

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| **Time** | **Content** | **Teaching Methods** | **Resources** | **Slides & Facilitator notes** |
| 15mins  10mins | Documenting PCSPs   * 1 page profiles   Discussion on recording in practice | Trainer led presentation  Q & A/discussion  Facilitated discussion | Slide set  It may be useful to have copies of any local recording templates | Slide 12-15 - There are many ways in which the person-centred information may be record as part of a PCSP. Organisations may use a specific record keeping format that will need to be used but there is usually way to ensure that the personalised information can be captured in this record e.g. an about me section. One way of capturing the information is through a 1 page profile. This provides a easily read summary of the information. One page profiles have been used in lots of settings, including planning with people at the end of their lives. There are some examples over the next few slides.  Slide 16 - Explain that there are 3 headings for the one page profile.  The appreciation section is a section that focuses on the things people like and admire about the person. The important to section describes all the things that are important to the person and the How to support me section describes what good support looks like to meet the persons’s needs and keep them safe and living well.  Slide 17 - This slide explores the key things we need to get right about one page profiles. We are looking for them to be detailed and specific enough that people will know exactly what they need to do you support somebody with the things that are important to them. Share a couple of examples to demonstrate this.  i.e. **reading** should be “**To always have a book to read before I go to sleep but it must be a fictional book otherwise I won’t be able to sleep. I currently use the Kindle on my i pad. I love to read crime novels**  Slide 18 -Discussion –   * How it works in general practice (documenting, sharing, reviewing). * Where might care plans be stored/ shared in the context of primary care? |