

**Proposal by CIRC RCGP / Marie Curie End of Life Care Steering Group
and
RCGP / Marie Curie Devolved Nations End of Life Care Leads
September 2016**

Proposal recommending to offer people nearing the end of their life the opportunity to participate in personalised care and support planning and to create and share their own personalised care plan.

Background:

The RCGP is committed to promoting personalised care and support planning across the UK. With a rapidly ageing society and changing patterns of illness many more people will live for longer and with increasing co-morbidities. Each year more of us will die and many more of us will face the challenges of dying, death and bereavement ^{1,2}.

In July 2016, the government's commitment to end of life care highlighted the importance of personalised, high quality care to everyone approaching or at the end of life ³.

Research from the British Medical Association shows that, judging how long a person may have left to live is one of the key challenges for doctors, in delivering good end of life care ⁴.

A shift in focus away from identifying people based on a clear prognosis of less than 12 months' life expectancy, and towards having conversations about supportive care during the last phase of a person's life may lead to people having conversations about end of life care earlier ⁵.

People with personalised care plans for end of life care, experience better quality of life near death, fewer hospital admissions and more hospice admissions ⁶. Compassionate and effective communication is fundamental to supporting people, and those important to them, to make decisions along their journey of care, in addition to understanding the relevant legal issues and documentation.

In 2015, RCGP was a founding member of the National Partnership for Palliative and End of Life Care which was collectively committed to accelerating improvements in palliative and end of life care. The Partnership produced: 'Ambitions for Palliative and End of Life Care: A National Framework for action 2015-2020' in September 2015 ⁷. This has refreshed the strategic direction for palliative and end of life care in England. One of the 8 foundations which underpin all six Ambitions is '**Personalised Care Planning**', which is described as:

'Everyone approaching the end of life should be offered the chance to create a personalised care plan. Many people with long term conditions or complex needs will already have a care plan and this should be updated to reflect their changing needs. Although participation must be voluntary, the opportunity for informed discussion and planning should be universal. These discussions should be between the person nearing the end of life, those important to them (as they wish) and their professional carers.'

The potential elements of the plan should be broad. This involves care and support planning discussions around treatment escalation plans, including cardiopulmonary resuscitation. It should allow people to express their preferences for care and set personal goals, highlighting what matters most to them. The offer should include the possibility of recording preferences that might guide others if the person were to lose mental capacity or the ability to express their preferences and make their own decisions (advance care planning). This is a voluntary process and may result in a written record of a patient's wishes, which can be referred to by carers and health professionals in the future. It may also encompass the chance to appoint a person with lasting power of attorney or allow the person to trust their professional carers to act in their best interests. Such conversations need to be handled with skill and sensitivity; they must be ongoing at the pace of the person and with options regularly reviewed, revisited and revised with the person and those important to them. At any stage, where people do not wish to accept the offer to discuss planning, this should be respected.

Proposal:

This proposal to RCGP Council recommends offering people nearing the end of their life the support and opportunity to participate in personalised care planning and to create and share their own personalised care plan.

Health changes during the final phase of life typically include increasing physical frailties. Personalised care planning might also include a commitment to provide evolving personalised self-care information. This information, alongside their wishes and preferences will allow those involved in their daily care (the individual and/or their carers) to develop a coherent and well informed network of care and support, with the views and wishes of the individual at its centre.

Good palliative and end of life care includes offering care and support to families, friends, carers and all those who are important to the dying person. This also includes offering good bereavement and pre-bereavement care. Consideration and involvement of social networks in our communities can be rewarding and offer demedicalised solutions to enable care and support to people at the end of life, those important to them and the bereaved. 8

With more people living with long-term conditions, proactive collaborative care and support planning (CC&SP) is gaining momentum as a core part of what it means to be a GP. **Every Moment Counts**, describes person-centred coordinated care near the end of life as a narrative: "I can make the last stage of my life as good as possible because everyone works together confidently, honestly and consistently to help me and the people who are important to me, including my carer(s)."9 Person-centred care allows health and care professionals to work in partnership with people and their carers to identify what matters most to them and then to work together to devise the most

appropriate plan to deliver this, recognising that a person's care needs will change over time, especially as dying and death approaches¹⁰.

Collaborative Care and Support Planning needs to be flexible around the individual's goals and the practice's resources. The concept has built on the existing models to provide a comprehensive six-stage process ^{11,12}.

Advance care planning is a component of personalised care planning and should be considered when deemed appropriate by the clinician and patient. This is not a tick box exercise. As a person progresses along their journey of care, personalised care planning conversations can be incremental with valuable information recorded at the person's pace over several conversations. For some people, particularly those who are diagnosed with an illness with anticipated loss of capacity, offering people information at or early in their diagnosis can give people the opportunity to plan and highlight what is most important to them. Others may prefer to have conversations at the point of a shift in treatment focus, significant deterioration of health or a life event. Good communication skills and understanding of key legal issues are crucial to enable meaningful discussion and decision making for people, and those important to them, requiring palliative and end of life care.

One Chance To Get It Right, describes advance care planning as a voluntary process of discussion about future care between an individual and their care providers, irrespective of discipline. An advance care planning discussion might include:

- the individual's concerns and wishes,
- their important values or personal goals for care,
- their understanding about their illness and prognosis,
- their preferences and wishes for types of care or treatment that may be beneficial in the future and the availability of these ¹³.

An advance care plan can guide a person-centred approach. It should be available to the person, so that they can review, change and update it themselves. Subject to that person's consent, or, if they lack mental capacity, in their best interests, the plan should also be shared with all those who may be involved in their care. MDTs play an important role in contributing to advance care planning discussions and making sure updated information is recorded and coordinated between relevant multi-professionals involved in their care.

We therefore ask that RCGP Council support the recommendation to offer people nearing the end of their life, the support and opportunity to participate in personalised care planning and to create and share their own personalised care plan.

Recommendations:

We recognise that, in order for advance care planning (as part of personalised care and support planning) to successfully gain uptake, support is required across the whole system. Our commitment to continue to improve care and support planning in the last years of life will include:

- Partnership working with relevant academic colleges, organisations and patient and carer involvement
- Seeking to continue to understand the experiences of palliative and end of life care for people and those important to them
- Championing excellence in education and training programmes to support multi-professionals to provide high-quality, compassionate and safe palliative and end of life care across the entire patient journey. Good communication and care planning skills are fundamental
- Supporting research development to learn from palliative and end of life care data across systems
- Growing inter-professional recognition of roles, responsibilities and resilience within multi-professional teams to deliver compassionate and personalised care and support planning ¹¹
- Enabling the public health, compassionate communities approach to develop in partnership with general practice as central hubs to continue to offer support for people, their families and carers with palliative and end of life care needs
- Supporting continued whole-system reduction in inequalities. For example, to understand better why people may be less likely to receive good palliative and end of life care, whether because of diagnosis, age, ethnic background, sexual orientation, disability, social circumstances, reduced access or resources
- Supporting the use of shared key information digitally (such as EPACCS) and in real-time so that consented information about the person's needs and preferences towards the end of life care be used to inform decision-making. Supporting people to have access, be able to contribute to this information and have a copy, either digitally or on paper depending on their preference
- Considering re-evaluation of our existing definition and approach to end of life care and practice, to incorporate personalised care and support planning from a much earlier stage. i.e. Considering how we plan for end of life with people but also how we plan for the rest of life and for the potential of increasing frailty. This may include transition from simply being focused on end of life choices to considering a process of learning how to adapt to and plan for all of the changes ahead, and to live as fully as possible
- Supporting commissioners to co-design integrated, patient-centred whole-system approaches ^{11,14}
- Championing funding to be directed to General Practice and supporting community teams in order to ensure that there is sufficient time, support, training, resilience, and resources to provide holistic, personalised care and support for people nearing the end of their life and to their families and carers
- Supporting each nation with ongoing development and activity. Noting terminology may differ accordingly.

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