

Palliative and End of Life Care

Covid-19 weekly information session Q&As - Thursday 14 May 2020

Ambition One: 'Each person is seen as an individual', focusing on Advance Care Planning

National Update – Prof. Bee Wee

Q: There was talk of guidance around Community Specialist Palliative Care Services, but this wasn't mentioned last week or this – can I ask what is happening with this please?

A: The changing context means that we have been asked to stand down this Standard Operating Procedure. Instead, we plan to publish a letter to clinical system leaders.

Q: Some hospices provide access to visitors outside last 24-48hrs, is this problematic now we have guidance which dictates visiting for patients at the very end of their life?

A: This is a policy decision for individual hospices to make. National guidance must cover all settings, so scope is broad. An important point that may make a difference to the hospice's decision is whether or not the patient is COVID positive. See appendix 2 of the guidance for more detail from PHE.

Q: Re: verification of death training, we are looking at developing training to support HCAs facilitating (not doing) remote verification – do you have any resource please?

A: We don't have training resources yet but have asked Skills for Care to develop this. Also, we have a flow diagram and template for the remote clinician, as supporting materials – these are available on the EOLC Practitioners' Network on Future NHS, email Sherree.Fagge@nhs.net for access, or request from england.covid-eolc@nhs.net.

Covid-19: Personalised approaches in the access to care and treatment - James Sanderson

Q: What is national's view on CMC as a platform for personalised advance care planning going forward? Is 'Coordinate My Care' appropriate for personalised care – does national have a view? It's London based.

A: Anything that facilitates the right conversation with the individual is really important. The Personalised Care Group have published a standard for considering what to look for in a personalised care planning tool/platform. As long as the chosen platform covers the areas discussed, then it will meet the expectation of a good personalised care and support plan.

Please find: <https://www.england.nhs.uk/personalisedcare/technology-to-support-personalised-health-and-care/>

We are in the process of updating this page with the latest work on digital, particularly in the context of COVID-19. For any enquiries relating to digital and personalised care please email england.personalisedcaredigital@nhs.net.

Q: The work on personalised care led by NHSE/I has been superb. It would be good to share this and work with ACP with colleagues in care homes. How do we share, including with independent sector?

A: The Framework for Enhanced Health in Care Homes references personalised care and support planning:

<https://www.england.nhs.uk/wp-content/uploads/2020/03/the-framework-for-enhanced-health-in-care-homes-v2-0.pdf>

'In developing the personalised care and support plan, it is good practice to follow the standard model of personalised care and support planning set out in Universal Personalised Care'

Q: What is being done to provide a web-based ReSPECT form that would enable a "live" document?

A: We understand from local intelligence that some areas are looking at integrating into local systems such as Coordinate My Care.

Q: Is there also an issue about learning and development and skills for all colleagues working in social care and health to be confident and capable in having discussions about EOLC and ACP?

A: There are lots of online training resources available for front line staff, including via Advance Care Planning Module in e-ELCA, <https://www.e-lfh.org.uk/e-elca-module-in-advance-care-planning-updated/>. Please see the slides from last week's session with links to resources produced and shared by other organisations.

Be Human: supporting people and families with Advance Care Plans and thinking ahead- Julie Stansfield

Q: Who is providing the advice?

A: There is an extensive panel of people with differing areas of knowledge and expertise. These include: National Guidance from NHSE & DHSC, practical process advice, legislative (human rights, Care Act), mediation & peer support. We can also reach out to the network for any specialist information required.

Q: An interesting point was raised recently with regard to EoLC within LD care homes and the support required for other residents who are confused/don't understand the loss of a fellow resident. The process therefore requires special considerations within this cohort.

A: On a roundtable earlier with Baroness Hollins she shared resources on the very issue of the loss of a loved one or someone you know. It is in easy read. Please find: <https://booksbeyondwords.co.uk/coping-with-coronavirus>

Q: Be Human – I assume covers Learning Disabilities (LD) as well as physical disability?

A: Be Human covers everyone, particularly people who receive support for any reason so yes this includes people with a learning disability. Also includes self-funders (those who pay for their own support and don't access public statutory care).

Advance Care Planning- Example of proactive approaches –NW Dr Debbie Harvey

Q: I am concerned that some people who may benefit from medical assessment and palliative care in hospital are not receiving this because of assumptions based on prior ACP decisions, even though this is now in context of acute infectious infection.

A: There is a risk. Education is key here and the fact that ACP can change and should be reviewed as circumstances change. There remains some misunderstanding from staff with respect to what an ACP is and means.

Q: I have been looking at the evidence base (rather than best practice or policy) for remote ACP consultation and not found much specific in the research base - is that your experience too?

A: Yes, in looking at this area there is very little research regarding remote ACP. There is evidence regarding other remote clinical areas such as telemedicine. As remote ACP increases, and perhaps becomes the norm, more research will evolve.

Q: Please could Debbie share with us a link to the MDU resource she mentioned?

A: Please find: <https://www.themdu.com/guidance-and-advice/podcasts-and-videos/practical-advice-on-consulting-with-patients-remotely>

Misc Questions:

Q: Please can I ask a question about how nationally personalised care is joining up with other national programmes? I.e. LTC

A: We are working with many partners, including the Primary Care Network and other streams that are focusing on long term conditions including Cancer and COPD. Our work also includes shared decision making and social prescribing.

Q: Are there any plans to gather evidence about developing ACPs remotely with children with life-limiting conditions and their families, conscious of the fact that this often happens with paediatricians and children's nurses?

A: We are not doing anything specifically on C&YP workstream at this time but is part of the specification. This will be on the agenda for the revived C&YP Board in Quarter 2.

Q: Is there any guidance out there for preparing patients for the conversations that we could refer them to?

A: The 'Unwelcome Conversations' suite on HEE has a range of resources available – this is detailed on the 'Resources produced by other organisations' slide from last week's session (along with lots of other helpful resources) and [also available here](#).

Q: Having seen a GP in real distress after having to have several phone ACP conversations - do we need to think of support for the professionals involved?

A: Definitely. There are quite a few resources available, e.g. <https://people.nhs.uk/> and <https://www.mentalhealthatwork.org.uk/ourfrontline/>. There is a check on front line workers wellbeing just developed, it has been shared in Ireland and will be shared across UK in the next 2 weeks. Specifically for primary care, there are excellent resources on the RCGP COVID-19 hub: <https://elearning.rcgp.org.uk/mod/page/view.php?id=10501>

Resources shared by members of the call

Northern Ireland hospice dementia and bereavement leaflet:

<https://www.nihospice.org/support-us/fundraising-and-events/events/supporting-a-person-with-dementia-following-bereavement-during-the-covid-19-pandemic>

Advance Care Planning video from Guy's and St Thomas' NHS Foundation Trust (3:13): <https://www.youtube.com/watch?v=dVspBW6l8RA>

Beyond words Covid-19 pictorial books: <https://booksbeyondwords.co.uk/>

Be Human movement: Report your experience of getting care or treatment during the Coronavirus (COVID-19): <https://be-human.org.uk/register-of-covid-19-experience/>

Mental Health at work: <https://www.mentalhealthatwork.org.uk/ourfrontline/>

Skills for care: COVID-19: Support and guidance for the adult social care sector:
<https://www.skillsforcare.org.uk/Home.aspx>