

Advance Care Planning virtually during a Pandemic

Introduction

The Marie Curie Virtual Advance Care Planning service was set up in response to the vulnerability of Care Home Residents during the Covid-19 crisis. Many Care Home residents and their families had not had discussions about their End of Life Care preferences recorded. Providing holistic, person-centred information and documenting preferences and clinical rationale for the transfer to hospital for those for whom it would be appropriate, is vital to enable the Health and Social Care system to provide better person-centred care.

Before the Pandemic Marie Curie London already had a commissioned Advance Care Planning (ACP) service in Ealing working alongside a dedicated GP team. As lockdown started in March 2020 the dedicated Nurses working in the Care Homes in Ealing were asked to support the Care Homes virtually instead.

Right across Marie Curie UK Nurses were shielding and the charity were contacted by numerous stakeholders to see what we could do to further support the pandemic. Many of our external Colleagues working in and supporting Care Homes had already identified that many residents in Care Homes did not have Advance Care Plans that were up to date and visible to 111 and the London Ambulance Service (LAS). For those that did have a plan there was a high degree of variation and quality of content. Marie Curie Nurses in London already had access to the Coordinate My Care (CMC) London's current Electronic Palliative Care Coordination system (EPaCCS) and so a virtual service was rolled out across parts of London to support Residents, Care Homes and GP's with discussing End of Life Care Plans and getting them written down.

Staffing

The service was set up during the time when the population in general was learning to use terms such as 'Shielding', 'Furloughing', 'Isolating', etc. The London manager advertised internally and recruited Registered Nurses from across the Charity nationally who would otherwise have been Furloughed due to the need to shield. At its peak, 20 Registered Nurses were working on the service, from different areas of work in Marie Curie including Hospice Nurses, Clinical Nurse Specialists, Practice Development Facilitators and other Marie Curie Registered Nurses who would normally have been visiting patients in their own homes during the night.

Mental Capacity

It came to light quite early on that many residents referred to the service lacked capacity. This led to a workstream with a dedicated team of GP's in Croydon to help us create a Best Practice model for Best Interests decisions. Marie Curie now have a verifying validation process which they complete remotely with the Office of the Public Guardian.

There has been lots of learning around Mental Capacity and Lasting Power of Attorney's. As well as the mandatory training all Marie Curie Nurses complete, extra training and resources around decision making were shared and disseminated.



Quality

Training was run alongside the service with support from many independent Hospices running ACP webinars and Hospital Consultants and Dr's delivering short sessions on various long term conditions.

A Quality Assurance Framework was created by the team at Marie Curie and shared with all those who commissioned the virtual service. A Monitoring Tool was developed and the Clinical/Quality Leads quality check at least 10% of all the plans created.

In meetings held with LAS the team have developed and learned how to create effective and detailed ACP records, not just concentrating on the mandatory fields in the record but also giving detail of conversation around Treatment Escalation Plans and Clinical Recommendations including non-pharmacological interventions (the softer stuff).

The service in South London also extended to patients in their own homes and Hospital Outpatients Departments, referrals for this coming from Consultants and Clinical Nurse Specialists of various specialities.

From April 2020 - March 2021 during the height of the pandemic Marie Curie ACP Service created 1,361 new care plans and reviewed and updated 313 existing plans across 11 London Boroughs.

Marie Curie Nurse - "I spoke to a lady who was the Lasting Power of Attorney for health for a very dear friend in a Care Home. This lady lived many miles away and was over 80 herself but very helpful and involved in her friends care. The lady told me her friend had had a difficult, troubled life and had no-one else. She said that all her life her friend to keep herself happy and calm had a teddy bear that she changed the tie on daily and this helped her cope. This information was invaluable to help the carers and anyone else who encountered her and it kept her calm so I added it to her Advance Care Plan."

Marie Curie Nurse - "Working virtually has allowed me to engage with patients and relatives globally in an empathic way in a relaxed and safe environment that was convenient for them".

Marie Curie Nurse - "It was an understatement when the residents son said that the past year had been 'very difficult'. Many families have shared with me the losses they have suffered due to Covid 19; often the resident themselves (having no mental capacity due to dementia/global brain injury) have no idea that the family member (in one instance their own husband) had died. It makes it even more important for me to be mindful when introducing the concept of the CMC and asking questions around ACP, that I remain open to whatever response they may have. ACP does not have to be finalised in one conversation. It should be an ongoing discussion.

Relative - "I feel I can open up to you even although I don't know you".

Relative - "Before this discussion with you making decisions seemed so black and white but now you've explained everything so clearly, I feel able to express my worries and concerns and feel confident to make the right decisions."

Marie Curie Nurse - "My husband works for 111 and he has been directing GP's to read the ACP (CMC) before visits which has really helped. He is not medical but because I am involved in ACP he now has this knowledge. Doing the ACP plans has also helped us reconnect with GP's as we have worked so closely with them during the pandemic."

Marie Curie Nurse - "Working on the ACP service I have had to learn new IT skills right from the word go as before I was very much a hands-on nurse".

Care Home residents daughter wrote to a Marie Curie Nurse - "It was really informative to talk to you. It's a tricky subject to talk about and you obviously had compassion and personal experience and spoke with great sensitivity. Thanks so much".

Marie Curie Nurse - "Many of the ACP's have been done for residents who lack capacity, so it has brought the mental capacity acts into real life and my understanding has increased"

Marie Curie Nurse - "It is not uncommon for LPAs of residents to be more guarded about this process (virtual discussion/phone call, from a 'stranger'); they often wish for some back up information, and a way that will verify my role. Of late several LPAs have requested access of the CMC plan, which I have facilitated. None of them have been 'unreasonable' but rather have showed concern and are clearly honouring their responsibility in holding the LPA."

Marie Curie Nurse - "As a nurse approaching retirement, I have enjoyed this and could see it as a way of using my skills learnt over 44 years to continue in nursing as much of what I have done could be used for revalidation. Practical nursing is a real challenge as you get older, but I could continue in nursing for longer using my skills developing other practitioners and myself."

Marie Curie Nurse - "Lockdown has caused a plethora of issues for relatives of residents in care homes, particularly significant for those who are also elderly and/or diagnosed themselves with long term conditions. They have needed to make hard decisions about how to go about their ongoing responsibilities for the residents concerned, and that has included how they themselves keep well and protected from possible Covid19 infection."



Case Study: Findings from CMC reporting in Ealing

Total number of records and views

Between September 2019 and June 2021, the Marie Curie team created 653 ACP records in Ealing. In total, these had been viewed 5,234 times, including 324 views by Urgent Care teams (Ambulance Service, 111 or A&E).

Quality Comparator

Table 1 presents the eleven CMC data quality comparator indicators. These indicators represent if this data has been included in the CMC, it does not evaluate the content. However, we know that completeness of information is crucial - as information not shared cannot be useful, whereas information shared may be useful.

Table 1. CMC Data Quality Indicators, comparing Marie Curie Ealing ACP project against Ealing Borough and North West London

Care Plan Creator	CEILING OF TREATMENT	CONTACT - PROFESSIONAL	CPR DECISION	CULTURAL / RELIGIOUS	FAMILY AWARENESS	PATIENT WISHES	PERSONAL CONTACTS	PPC	PPD	PROGNOSIS	SYMPTOM/TREATMENT PLANS
Marie Curie	100%	1%	98%	88%	55%	59%	84%	99%	90%	100%	6%
Ealing Borough	100%	3%	87%	9%	20%	24%	39%	93%	80%	100%	25%
North West london	100%	6%	88%	10%	19%	24%	40%	89%	77%	100%	32%

As shown in Table 1, Marie Curie created CMC records that exceeded completion levels in seven of the eleven areas. Most notably, there are substantially higher levels of completion in the Cultural/Religious, Family Awareness, Patient Wishes, Personal Contacts and Preferred Place of Death domains. This service is designed to be delivering holistic conversations about what is important to care home residents, and this provides a positive indication that the service is delivering in this respect.

The Marie Curie service matches the comparator areas in terms of Ceiling of Treatment, Preferred Place of Care and Prognosis.

The only field where there is a substantially lower level of completion for the Marie Curie created CMC records is the Symptom Management field. However, this is because the Marie Curie service team are often speaking to care home residents at a early stage and many clients may not have an advanced symptom profile at the stage that the CMC plan was created.

Whilst the Ealing service has returned to face to face visiting Marie Curie London's ACP service has now become 'Business as usual' with a small virtual workforce. Marie Curie Registered Nurses continue to support Care Homes and their residents across London.



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