Anticipatory Care Planning and Neurological Conditions

Webinar
Wednesday 25 August 2021
13:00 – 14:00

Improvement Hub
Enabling health and social care improvement
Welcome

Tom McCarthy
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Primary Care Improvement Portfolio
1. **Open and close the chat panel** – use the chat panel to introduce yourself, raise any questions you may have for the speakers and also post comments.

2. **Turn your camera off and on** – please ensure your camera is turned off to minimise bandwidth issues.

3. **Mute and unmute yourself** – please mute yourself to avoid any background noise.

4. **Leave the meeting**
This Webinar will be recorded

The link will be shared, so those who are unable to join us today can listen to the session.

Please do not record the session.
Introduction
Introduction

Judith Newton
Lead MND Nurse Consultant
Scottish Government
It’s all about the CAT!

- **C**onfidence
- **A**bility to start the conversation
- **T**ools
How Anticipatory Care Planning has made a difference for people with MS and MND in Orkney.
Moira Flett
MS and MND Advisor
NHS Orkney
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Triggers

• Frequent unscheduled contacts.
• When approaching the end of life.
• Unstable or deterioration in their condition.
• Decline in health of main carer or an elderly main carer.
• Decline in cognitive function.
• At risk of losing ability to communicate.
• ALSO if person has dependants (child, elderly relative) so that dependants’ care is planned should the person have a relapse or deterioration in condition.
Bringing up the ACP conversation

- Create opportunities to discuss – prompts on assessment/review proforma to ask about PoA and ACPs.
- Benefits of expressing and recording wishes also still beneficial if don’t have strong wishes.
- Be alert to cues.
- Have a blank ACP at hand.
The conversation

• Include person and family members/Power of Attorney.
• Realistic.
• Allow time for them to discuss themselves.
Difference to the person

- Allows them to express their wishes and consider options regarding their care and support e.g. what they want, what they don’t want, DNACPR, preferred place of care and death (nearing end of life).
- Plans in place taking account of what matters to them e.g. family, staying at home, faith, pets.
- Reassurance that family are aware of wishes and plans, to reduce family stress.
Difference to the family / Power of Attorney

• Opens up topic for discussion.
• Previously had worried about what would happen if they became ill.
• Reduces the chances of them having to make decisions on person’s behalf in stressful/emergency situations.
• Helps avoid guilt or family conflict re decisions they made.
• Helps avoid unrealistic expectations/high care burden being put on family.
• Provides an opportunity for them to express concerns so we can then support them with this.
• Ensures family aware of where all necessary documentation stored e.g. ACP, PoA, DNACPR, Getting to Know Me.
• For dependants, it helps ensure care is planned for them should this be required.
Difference to the health and care services involved

- Allows a deeper conversation to help us have a better understanding of what matters to a person and their family, which helps guide our future conversations and approach to their care.
- A coordinated approach to ensure all necessary services are aware and can meet person’s wishes and support the family.
- Improved team working and communication.
- Realistic healthcare.
- Helps avoid low value/unwarranted treatments or hospital admissions.
- Sense of satisfaction, comfort and closure (person-centred, supported to live and die their way).
AHP’s role in neurological conditions
Rosalind Gray

Head of Therapies at Nightingale Hammerson

Occupational Therapist, 26 years experience
Worked across NHS, Local Authority, Private and Charity sectors in London, focusing on palliative care in the last few years
I’d like to tell you about my lightbulb moment.....

Presenting an experiential perspective of my role and journey in ACP and my passionate belief that AHPs have a vital role to play in ACP work

I wish I’d know then what I know now.... I’ll take you on a journey
Before my lightbulb moment, I was already:

- Hopes, dreams, aspirations
- Who’s important in my life?
- What does the future look like?
- What’s important to me?
- What compromises am I willing to make?
- Legacy
- Managing change
- Change in function
- What brings meaning to my life
I was already supporting people with ACP but perhaps not recognising it. The lightbulb moment came with the opportunity to understand ACP better and the active role I could play.

More importantly, being involved in ACP resulted in:

- Person-centred care with wishes respected. People being actively involved and in control of how they want to live life and what’s important to them

- Family/network feeling supported and included. This is particularly important if young children are involved.

- Crisis reduction and better use of resources i.e. knowing what the plan is, avoiding unnecessary hospital admission, timely referrals to other agencies.

- Planned care with a common goal and enhanced multidisciplinary working
ACP is and should be so much more than what we traditionally think about:

- Preferred place of care (PPC)
- Preferred place of death (PPD)
- Ceiling of treatment
- CPR status
- LPOA
- Making a will
- Anticipatory/injectable medication
- Wishes after death e.g. cremation/burial
Why AHPs should support ACP for people living with neurological conditions

Early intervention, often 1st involved

Established Relationship

ACP should not be a medical model only

Ongoing conversation at person’s pace

Already thinking ahead e.g. disease progression, planning for the future

Focusing on living life and making the most of every moment

Holistic perspective including psychosocial, and spiritual needs. Understanding grief/loss.

Enabling the person to be control, actively participate and do what matters to them.

Advance communication skills – used to sensitive conversations

Conditions e.g. dementia – planning early

Voice-banking

Used to complexity

Skilled supporting people with cognitive or communication changes

Already working with families, networks and communities

Neuro-specific resources, support groups, funding options. Awareness of likely progression to be a step ahead with planning

Notice functional changes early e.g. SCC, decreased mobility
A few tips moving forward:

• Seize those moments – be ready for discussions at any time
• Get to know your local palliative care team (shadow if you can)
• Work closely with your multidisciplinary team – team effort
• Use ACP language – (this includes not being afraid of the word ‘dying’)
• Get used to the silence – be with someone in the moment, listen, ask questions without having to goal set/solve the problem etc
• **Communicate** and **write ACPs down** – use local resources e.g. CMC in London. Support clients to do this.
• Tap in to resources e.g. Toolkits, books, podcasts, training, neuro charities, special interest groups etc
ihub ACP
Programme update
Presenter

Adeline Tan
Improvement Advisor
Primary Care Improvement Portfolio
4 steps to ACP: Toolkit

1. Preparation and planning
2. Meaningful conversations
3. Documentation and sharing
4. Regular review
Step 1 – Preparation and planning

1. Preparation and planning

- Identifying who will benefit most from an ACP/KIS
- Exploring what resources you have within your team for ACP
- Everyone should be involved
- Preparing both yourself and the person for the conversation
Step 2 – Meaningful conversations

REDMAP framework developed by Dr. Kirsty Boyd

- **READY** - Can we talk about your health + care?
- **EXPECT** - What do you know/want to tell or ask me?
- **DIAGNOSIS** - We know/don’t know what is important to you/your family?
- **MATTERS** - What we can do/this will not help
- **ACTIONS** - Let’s plan ahead for when/if
Step 3 – Documentation and sharing

Using appropriate tools such as:

- KIS
- ReSPECT
- My ACP
- Essential ACP Online Tool
The Impact of Covid-19

Percentage of patients with a KIS from Jun 2017 to Jun 2021
A word on tools

• Don’t focus on the tool alone
• Focus should be on the **conversation** with the person, their families, carers or legal proxies
Step 4 – Regular review

- Take a pragmatic approach and focus on the KISs which will make a difference.
- Consider how best to use your whole team, in particular admin, practice nurses, community nurses, extended MDT, GPs.
Summary and next steps for 2021-22

1. Preparation and planning
2. Meaningful conversations
3. Documentation and sharing
4. Regular review
Discussion Time
Next steps

1. Evaluation survey – link in the chat box
2. Publish a summary on ihub website
3. Circulate a follow up email
Keep in touch

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To find out more visit: ihub.scot/acp