



Anticipatory Care Planning and Neurological Conditions

Webinar

Wednesday 25 August 2021

13:00 – 14:00

Improvement Hub

Enabling health and
social care improvement



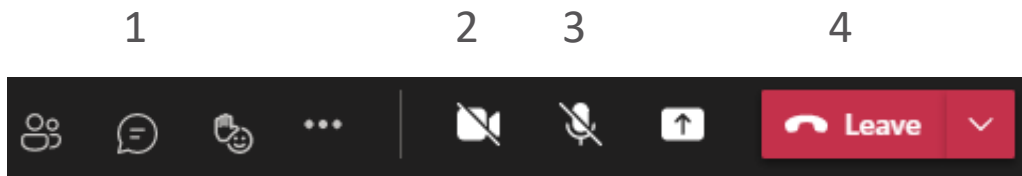
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Welcome



Tom McCarthy
Senior Improvement Advisor
Primary Care Improvement Portfolio

Housekeeping



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

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Introduction



Judith Newton
Lead MND Nurse Consultant
Scottish Government



Scottish Government
Riaghaltas na h-Alba
gov.scot

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.

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Presenter



Moira Flett
MS and MND Advisor
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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

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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

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'd like to tell you about my lightbulb moment.....



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,
aspiration
s

Legacy

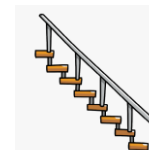


Who's
important
in my life?

What does
the future
look like?

What compromises
am I willing to
make?

What's important
to me?



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



Everything else!

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

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

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

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



**nightingale
hammerson**



ihub ACP Programme update

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Presenter

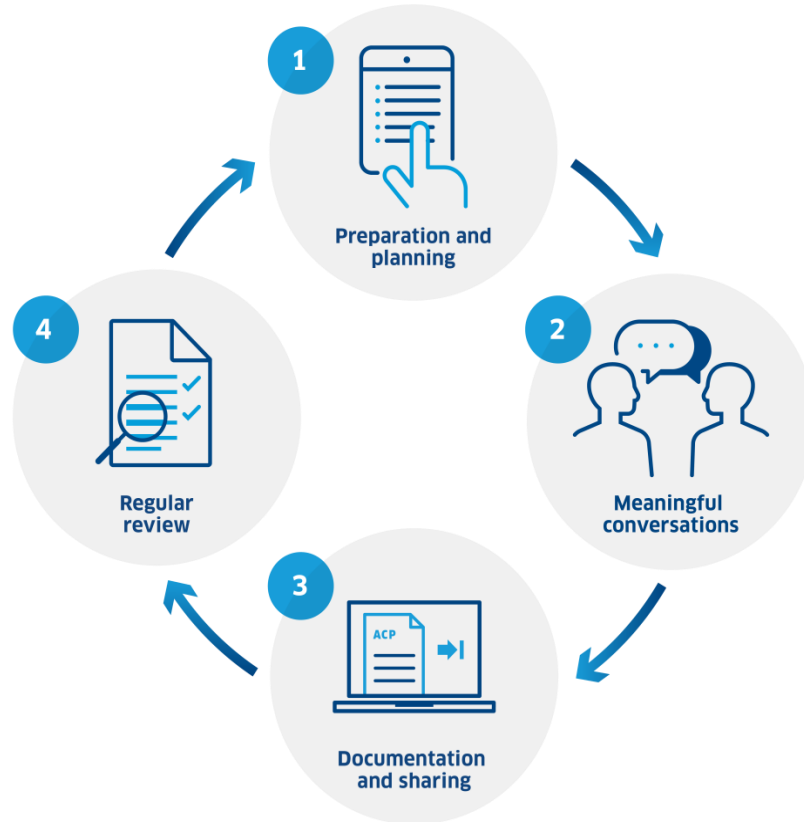


Adeline Tan

Improvement Advisor

Primary Care Improvement Portfolio

4 steps to ACP: Toolkit



Step 1 – Preparation and planning

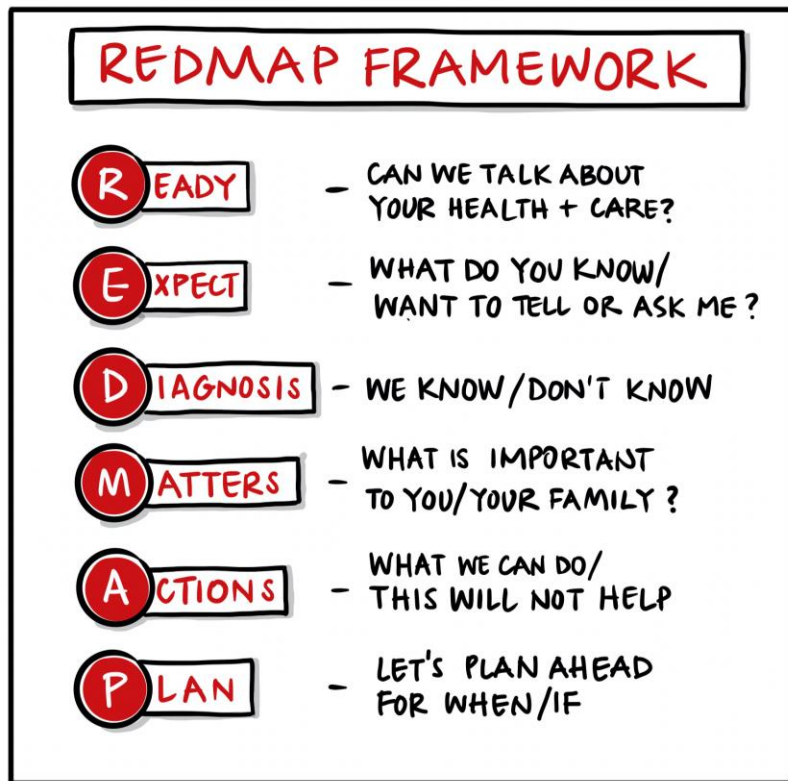
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**Preparation and
planning**

- 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



Step 3 – Documentation and sharing

3

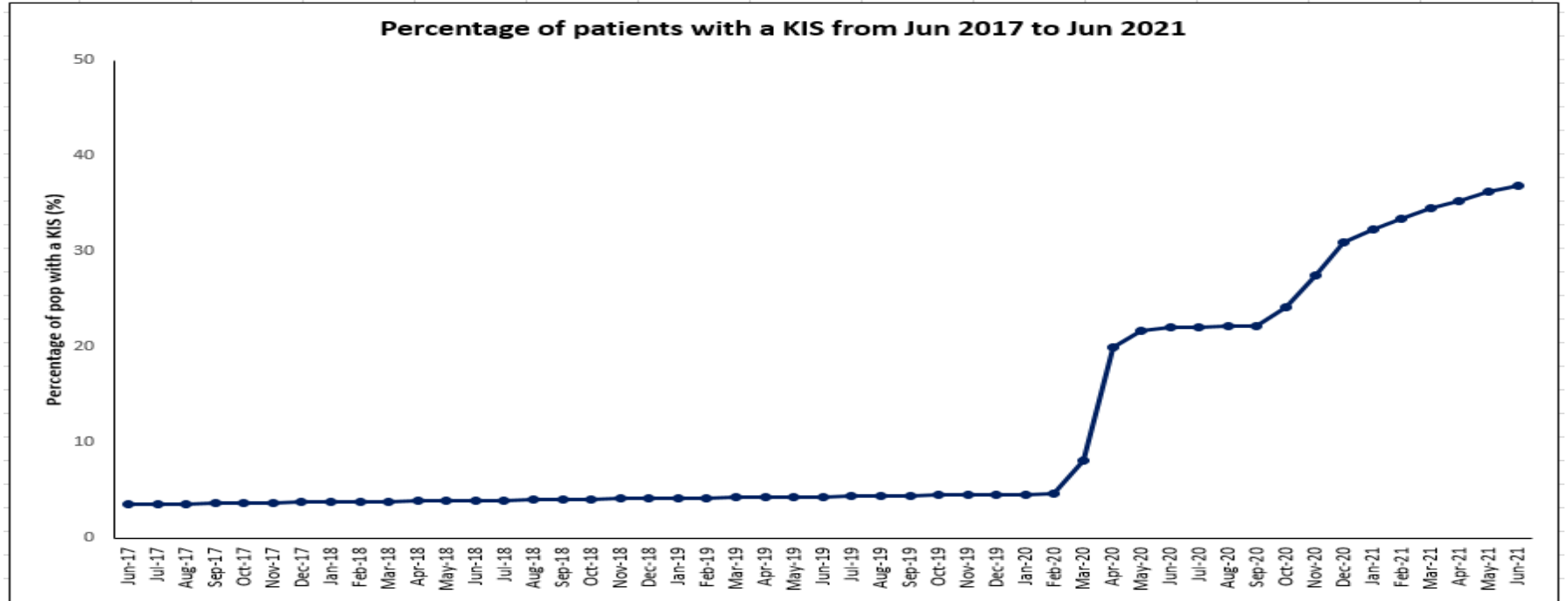


**Documentation
and sharing**

Using appropriate tools such as:

- KIS
- ReSPECT
- My ACP
- Essential ACP Online Tool

The Impact of Covid-19



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

4



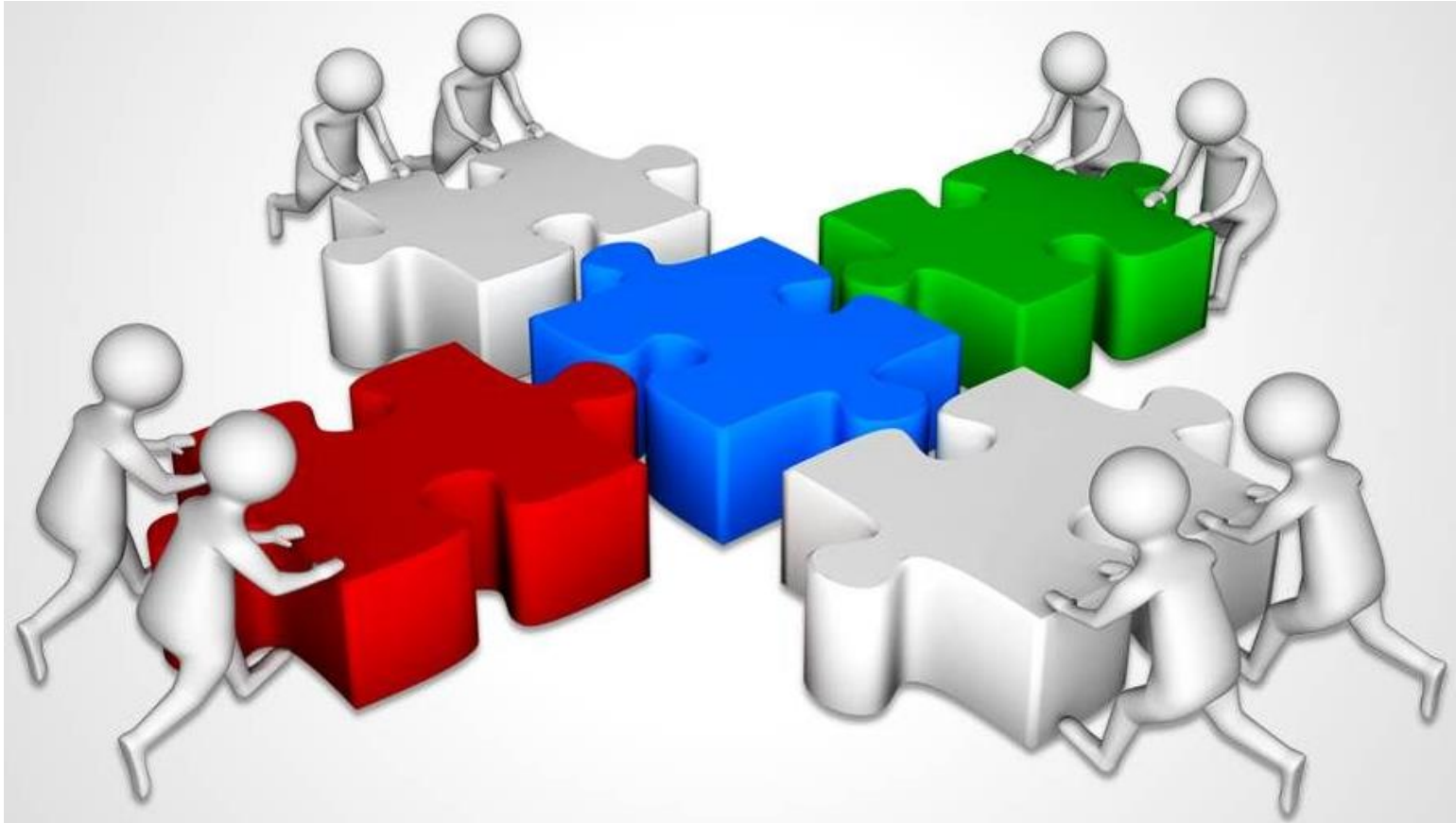
**Regular
review**

- 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



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

 his.pcpteam@nhs.scot

 @SPSP_PC #ihubACP

 To find out more visit: ihub.scot/acp