Neurological Diseases and Palliative Care

St Clare Hospice
Hand in hand we care

LEARNING TOGETHER STUDY DAY

25th June 2024

stclarehospice.org.uk
Registered Charity No. 1063631

Caroline Ashton-Gough

Advance Care Planning with neurological diseases

In partnership with

Future Care Planning and Neurological Disease

Caroline Ashton-Gough

Admiral Nurse/Dementia Clinical Nurse Specialist

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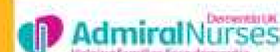

What do Admiral Nurses do?

In the core areas of practice, Admiral Nurses provide:

- A family and relationship centred approach
- Specialist assessments and evidence-based interventions for families affected by dementia with complex needs
- Clinical, pschological and social support for family carers and people living with dementia, particularly during periods of transition
- Liaison with other professionals/organisations
- Education, consultancy and supporting changes in practice

Community

Supporting carers to look after a person with dementia at home

Coordinate care/case management

Help transition into care if required

Deliver education and collaborate with agencies to improve quality of care

Post diagnostic support with families

Care home

Engagement and support with families in the care home

Identifying and supporting those with complex needs

Manage co-morbidities and frailty

Provide education, coaching and training to care home staff

Facilitate a positive culture within care homes

Acute Hospital

Support of family carers in hospital

Manage co-morbidities and frailty

Provide education for hospital staff

Work alongside and support clinical/ward staff

Preventative management of risks to health

Facilitate effective discharge

Support transitions

Hospice

Support of family carers and people with dementia in the hospice

Identify and support complex end of life care challenges

Provide education to hospice staff and carers on end of life care and dementia

Support of carers during transitions

Raise awareness of dementia being a life-limiting illness

Admiral Nurse Clinics

Support for family carers in community settings

Provide advice on complex care issues

Signposting to other services

Case management

Workforce carer support and advice

Admiral Nurse Dementia Helpline

One-to-one support and advice for families, professionals and others affected by dementia UK-wide

Support to families affected by dementia who do not have access to an Admiral Nurse in their locality

Provide direct access to an Admiral Nurse through telephone and email seven days a week: 9am-9pm Monday to Friday and 9am-5pm at weekends

What is Advanced Care Planning

"An advanced care plan or advanced statement is a written statement that sets out your wishes, beliefs, values and preference about your future care. It provides a guide to help healthcare professionals and anyone else who might have to make decisions about your care if you become too unwell, to make decisions or to communicate them"

Sue Ryder

Advanced Care Planning

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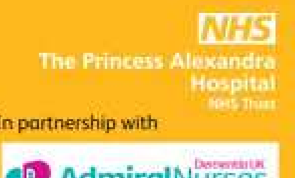
Advance Care Planning

- *What you want*
  Statement of wishes and preferences
- *What you don't want to happen*
  Advance decisions to Refuse Treatment
- *Who you want to speak for you*
  Lasting power of attorney

Who needs an ACP

Anyone, of any age, life limiting diagnosis

Neurological Conditions



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A neurological condition is any condition that affects the brain, spinal cord and/or nerves

Dementia
Epilepsy
Parkinson's
Huntington's
Multiple Sclerosis
Progressive Supranuclear palsy (PSP)
Stroke

Neurology Palliative Care Challenges

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Long duration of neurological Illnesses
Recognition of end of life phase
Potential sudden death (MND)
Lack of predictable course of illness
Complex multidisciplinary Care
Specialist treatments (PD Deep brain stimulation)
Neuro-psychiatric problems
Rapidly advancing disease means some may need palliative care early
Many die but not from the neurological condition
Planning end of life care can be challenging
Cognitive changes, need for planning early on in illness
Communication
Care environment

What is Dementia

Dementia

Dementia is a progressive, life limiting illness

Up to 200 sub-types

There is approximately 960,000 people living with dementia in the UK

NICE (2018) recommends that we offer early and ongoing opportunities for people living with dementia and people involved in their care

What should we consider

The importance of having an Advanced Care Plan in place for the older person, those who are frail, and those with serious medical conditions in the COVID-19 Pandemic

Where a person has capacity (as defined by the Mental Capacity Act) this Advanced Care Planning should always be discussed with them directly

Where a person lacks the capacity to engage with the process then it is reasonable to produce a plan following Best Interest Guidelines with the involvement of family or other appropriate individuals

Should be individually considered with no blanket policies

What should we consider

- Advanced statements
- Preferred Priorities of Care
- DNACPR forms
- This is Me

What should we consider

Formal documents-legally binding
Lasing power of attorney for finance and/or health

- Advanced decision to refuse treatment (ADRT)

Advanced Decision to refuse treatment

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An ADRT is a legally binding document. It needs to be signed dated and witnessed and VERY specific (e.g. I do not want antibiotics for a chest infection if I can no longer eat or drink unless they will help reduce my pain)

A recorded DNACPR decision is not, in itself, legally binding and should be regarded as a clinical assessment and decision, made and recorded in advance, to guide immediate clinical decision-making in the event of a patient's cardiorespiratory failing

Barriers to completing an ACP

	Communication Difficulties
Waiting for the HCP to initiate a discussion by the patient	Changes with memory Attention and concentration Unpredictable prognosis
Waiting for the patient to initiate a discussion by the HCP	Procrastination , or waiting to do it later Dependence on family for decision making Lack of knowledge Believing a lawyer is needed to fill out the forms Fear of signing my life away Not being treated

When do we start ACP

Patient asks you or tells you

Life changing event

After multiple hospital admissions

At a new diagnosis of a life limiting condition such as dementia

Last year of life "surprise question" GSF

General frailty and multiple co-morbidities

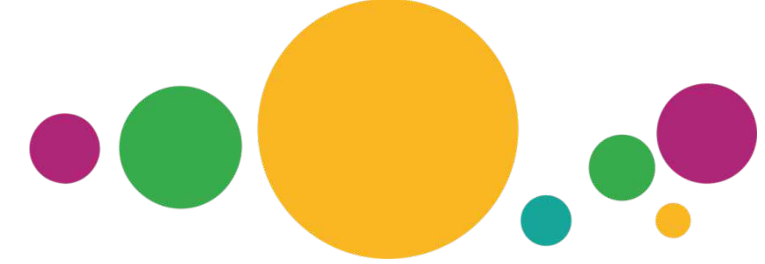
Why do we need ACP

Reduce uncertainty

Wishes are planned, communicated and undertaken

Prevent unwanted/unnecessary hospital admissions

More home based care



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Importance of ACP for PLWD

- Advanced Care Plan
- Care Setting
- DNACPR
- Eating Problems
- Hospice
- Hospital

Importance of ACP for PLWD

- Dementia is a progressive and irreversible neurodegenerative disease and is life limiting
- In the UK by 2040 there is expected to be 1.6 million people living with dementia
- It is estimated 1 in 3 , over the age of 65, will die from or with dementia (Cambridge Study)
- Distressed reactions misinterpreted as behaviours in dementia
- Research evidence and (media coverage) suggests that PLWD receive poor EOL care
- Lack of emphasis on dying without pain and with dignity and respect

Why we need to think differently

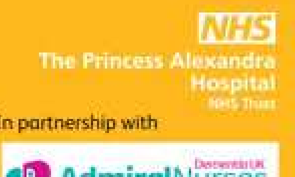
Usually we may wait to advanced stages of disease to discuss end of life care preferences

We may not consider palliative care until "active intervention" is no longer beneficial

BUT
In dementia, loss of mental capacity occurs early in the disease

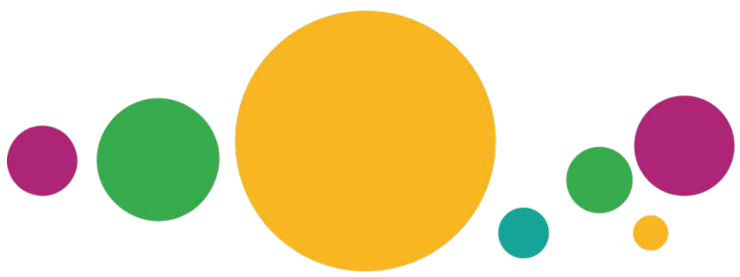
It may be necessary to combine palliative, supportive and active care to appropriately manage needs

Summary



GSF five step to Advanced Care Planning

1. Think
2. Talk
3. Record
4. Discuss
5. Share

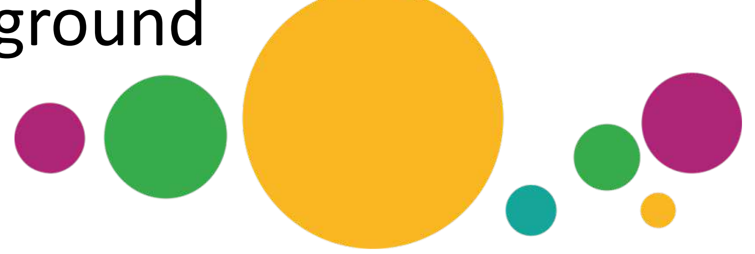


Facilitation of Conversations

ACP is an ongoing process that may take many conversations

Take into account the persons

- History
- Social circumstances
- Wishes and feeing's
- Beliefs, including religious, cultural and ethnic background
- Aspirations
- Any the factors they feel are important



Facilitation of Conversations

- Use patient cues
- Take time, really listen and be present
- Discuss recent events, hospital appointments or admissions
- Ask them who they want involved-family, friends or advocates
- Help them consider whether involving a healthcare professional could be useful

POS Palliative care Outcome Scale

POS measures are a family of tools-physical, psychological, emotional and spiritual

Validated instrument , can be used in clinical care, audit, research and training
Specifically designed for sue among people severely affected by disease such as cancer, respiratory, heart, liver or renal failure and neurological disease
POS measures are used globally, can be downloaded from website in 12 languages

IPOS-Dem
IPOS-Neuro
IPOS-Renal
Publications/Training [Palliative care Outcome Scale (POS) - Home (pos-pal.org)]

Facilitation of conversations

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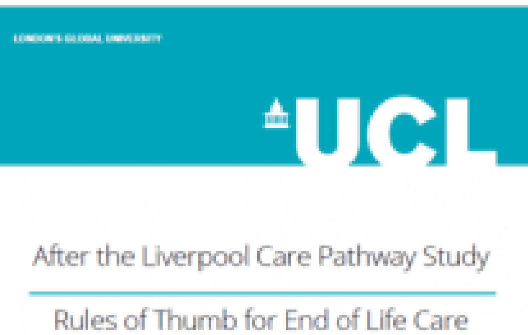
Created as part of a research project funded by Marie Curie/AS

Guide for HCP providing care and support for PLWD

Can be used for training, support decision making

Help with discussions with family members and advocate

1. Eating or Swallowing difficulties
2. Agitation or restlessness
3. Reviewing treatment and interventions at the end of life
4. Providing routine care



Facilitation of conversations

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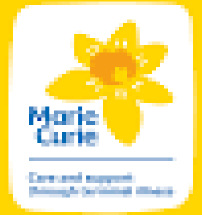
Information for family and friends as dementia progresses towards the end of life

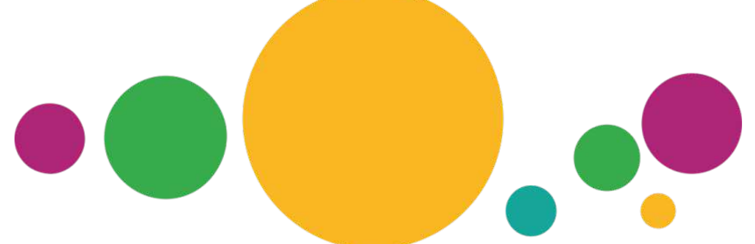
Marie Curie/UCLH

Helps to make decisions, provide care, plan for future care, help to guide discussions with HCP

Eating and drinking

Information for family and friends as dementia progresses towards the end of life





Advanced Care Planning

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My Advance Care Plan

My details:

My Name:

Date of Birth:

Address:

Postcode:

Telephone:

Mobile:

Name of Proxy/Next of Kin 1:

Name of Proxy/Next of Kin 2:

Heading (Arial bold)

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https://www.youtube.com/watch?v=Z8l8npWtnUI

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"Every single day is precious, don't waste a moment" (Rob Burrows, 2024)

Rob Burrows 1982-2024