Using Talking Mats in Palliative and End of Life care

Sally Boa

Plan

- Thinking ahead – challenges and opportunities
- Thinking Ahead Resource
- Examples from practice
- Discussion

Thinking ahead

- *How easy do people find it to talk about death and dying?*
- *What might get in the way?*
- *Why might it be important?*

We know that…..

Having discussions about end of life plans can:

- enable people to remain in control for longer
- help them to identify the care and support they need
- result in less invasive treatment
- provide comfort and reassurance

Aline De Vleminck et al, 2013

Tasmin et al 2015

McCune, 2016

However……..in Scotland

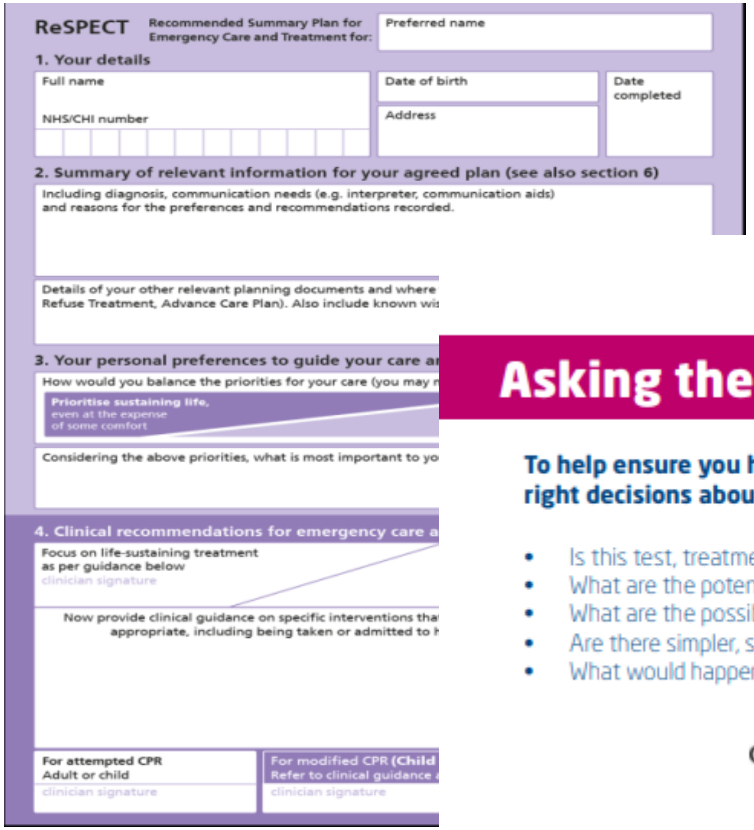
- 74% of people have not discussed what their wishes would be if they did not have long to live
- 79% of people don't have any written plans for their end of life care, financial wishes or funeral plans
- Only 35% of people have written a Will

https://www.goodlifedeathgrief.org.uk/content/evidence/

It’s well recognised that this is a national problem!

- http://ihub.scot/anticipatory-care-planning-toolkit
- www.goodlifedeathgrief.org.uk
- www.dyingmatters.org
- http://www.sad.scot.nhs.uk/video-wall/

Documents, resources and processes that support us


ReSPECT

Recommended Summary Plan for Emergency Care and Treatment for:

Preferred name

1. Your details

Full name

NHS/CHI number

Date of birth

Address

Date completed

2. Summary of relevant information for your agreed plan (see also section 6)

Including diagnosis, communication needs (e.g. interpreter, communication aids) and reasons for the preferences and recommendations recorded.

Details of your other relevant planning documents and where
Refuse Treatment, Advance Care Plan). Also include known wi

3. Your personal preferences to guide your care a

How would you balance the priorities for your care (you may

Prioritise sustaining life, even at the expense of some comfort

Considering the above priorities, what is most important to yo

4. Clinical recommendations for emergency care a

Focus on life-sustaining treatment as per guidance below

clinician signature

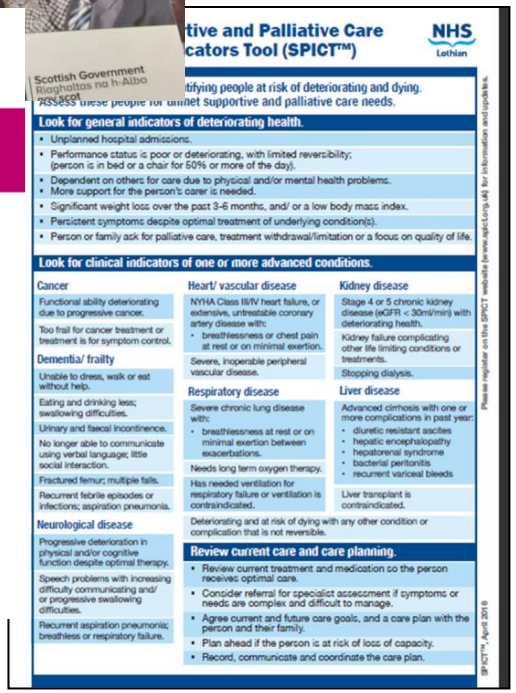
Now provide clinical guidance on specific interventions tha
appropriate, including being taken or admitted to

For attempted CPR
Adult or child

clinician signature

For modified CPR (Child
Refer to clinical guidance

clinician signature


tive and Palliative Care
cators Tool (SPICT™)

NHS Lothian

tifying people at risk of deteriorating and dying.

Look for general indicators of deteriorating health.

- Unplanned hospital admissions.
- Performance status is poor or deteriorating, with limited reversibility; (person is in bed or a chair for 50% or more of the day).
- Dependent on others for care due to physical and/or mental health problems.
- More support for the person's carer is needed.
- Significant weight loss over the past 3-6 months, and/ or a low body mass index.
- Persistent symptoms despite optimal treatment of underlying condition(s).
- Person or family ask for palliative care, treatment withdrawal/limitation or a focus on quality of life.

Look for clinical indicators of one or more advanced conditions.

Cancer
Functional ability deteriorating due to progressive cancer.
Too frail for cancer treatment or treatment is for symptom control.

Dementia/ frailty
Unable to dress, walk or eat without help.
Eating and drinking less; swallowing difficulties.
Urinary and faecal incontinence.
No longer able to communicate using verbal language; little social interaction.
Fractured femur; multiple falls.
Recurrent febrile episodes or infections; aspiration pneumonia.

Neurological disease
Progressive deterioration in physical and/or cognitive function despite optimal therapy.
Speech problems with increasing difficulty communicating and/ or progressive swallowing difficulties.
Recurrent aspiration pneumonia; breathless or respiratory failure.

Heart/ vascular disease
NYHA Class III/IV heart failure, or extensive, untreatable coronary artery disease with:
- breathlessness or chest pain at rest or on minimal exertion.

Severe, inoperable peripheral vascular disease.

Respiratory disease
Severe chronic lung disease with:
- breathlessness at rest or on minimal exertion between exacerbations.

Needs long term oxygen therapy.
Has needed ventilation for respiratory failure or ventilation is contraindicated.

Deteriorating and at risk of dying with any other condition or complication that is not reversible.

Kidney disease
Stage 4 or 5 chronic kidney disease (eGFR < 30ml/min) with deteriorating health.
Kidney failure complicating other life limiting conditions or treatments.
Stopping dialysis.

Liver disease
Advanced cirrhosis with one or more complications in past year:
- diuretic resistant ascites
- hepatic encephalopathy
- hepatorenal syndrome
- bacterial peritonitis
- recurrent variceal bleeds

Liver transplant is contraindicated.

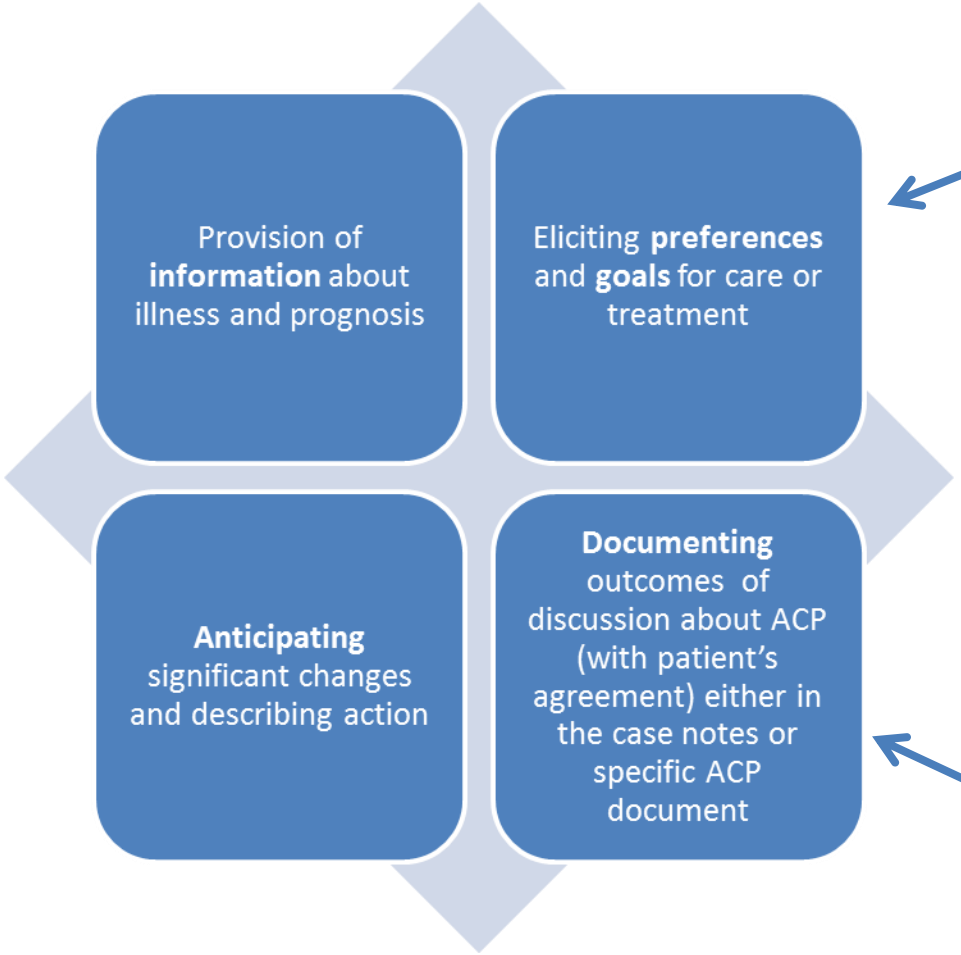
Review current care and care planning.

- Review current treatment and medication so the person receives optimal care.
- Consider referral for specialist assessment if symptoms or needs are complex and difficult to manage.
- Agree current and future care goals, and a care plan with the person and their family.
- Plan ahead if the person is at risk of loss of capacity.
- Record, communicate and coordinate the care plan.

Add into the mix …..

- Aphasia
- Dysarthria
- Cognitive impairment
- Family dynamics
- Uncertainty around prognosis
- Hospital admission
- etc……

ACP principles

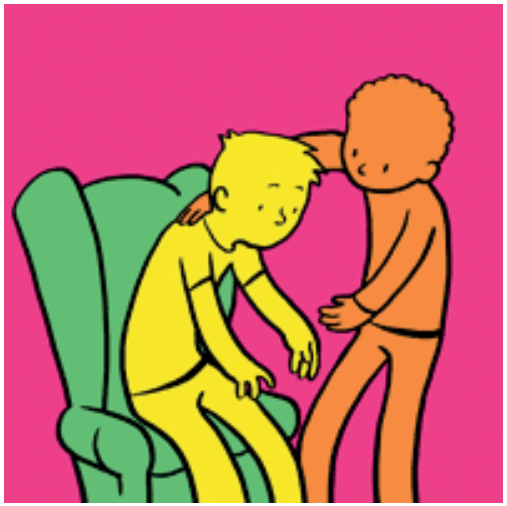


Development of the resource

- 16 staff at Strathcarron trained to use Talking Mats (accredited trainers scheme)
- Sub group of staff worked on developing symbol sets for ACP
  - 3 symbol sets
- Workshop held at Highland hospice
- Symbol sets developed and refined
- Symbols trialed with a range of people living with long term conditions

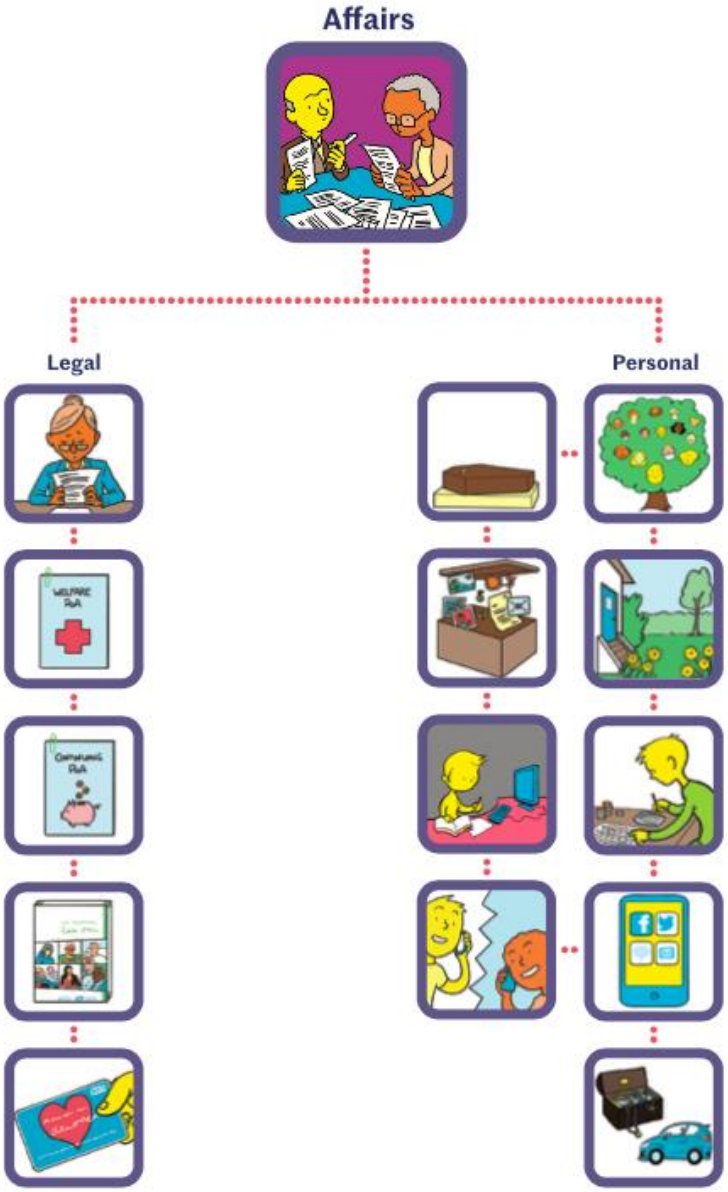
Thinking Ahead Resource

Affairs



Care/Treatment

Personal values


Affairs
Legal
Personal
WELFARE
PoA


Will
Informing people
Social media/passwords
Organ donation
Home and garden
Finances
Leaving memories
Funeral
Affairs
CONTINUING PoA
Continuing POA finance
WELFARE PoA
Welfare POA health

Care/Treatment

Place of care

Who gives the care

Purpose of care/treatment


Other members of family
NUTRICIA
Nutilis
clear
Own home
Family
Prolonging life
Staff
Hospice
Emergency treatment
Acute hospital
Volunteers
Friends
Community hospital
Day care
Symptom management
Care home
Care/Treatment

Personal Values

People

Personhood

Existential

Involvement


Making decisions
Taking risks
Sense of humour
Identity
Pets
Family
Being active
Appearance
Spirituality
Intimacy
Maintain Independence
Finding peace
Privacy
Being listened to
Personal values

What people said…..

"This is really making me review my situation"

"Afterwards I really don't know how to explain it but I felt a ton weight off my shoulders, I now know everything I need to know. More important for me I'll never need to discuss it again … the book will be locked away safe and we can get on with our lives"

"Made me think and realise that these are very important issues that need to be talked about with my husband and family"

"I am surprised to find I had lots of cards on the positive side – that makes me feel good"

"I hadn't sorted out as many things as I thought I had"

"It helped us discuss differences openly and frankly"

Discussion

- When would you use it?
- How would you use it?
- How would you introduce it?
- What would you do with the information?

Resources

- All About me (Strathcarron Hospice)
- Lets talk about it : Dying Matters
  - https://drive.google.com/file/d/0B3vmSe1_duxIU2M4WFVYd1BRNjQ/view
- Good Life, Good Death, Good Grief
  - https://www.goodlifedeathgrief.org.uk/content/acp-origami-game/
- Blogs:
  - http://www.talkingmats.com/talking-mats-to-support-conversations-in-a-hospice-setting/
  - http://www.talkingmats.com/advance-care-planning-lorraines-story/

References

- Aline De Vleminck, Dirk Houttekier, Koen Pardon, Reginald Deschepper, Chantal Van Audenhove, Robert Vander Stichele & Luc Deliens (2013) Barriers and facilitators for general practitioners to engage in advance care planning: A systematic review, Scandinavian Journal of Primary Health Care, 31:4, 215-226, DOI: 10.3109/02813432.2013.854590

- Sinuff Tasnim, et al. "Improving end-of-life communication and decision making: the development of a conceptual framework and quality indicators." Journal of pain and symptom management 49.6 (2015): 1070-1080.

- Susana Lauraine McCune. "Advance care planning." *Encyclopedia of global bioethics* (2016): 38-46.