

PACE Steps to Success Programme

Tools

Date of publication

31st January 2019



Looking and Thinking Ahead

A document to inform decisions about future care preferences and wishes for people living in care homes.

This document has been produced to help care home staff to open up discussions about future care with frail older people living in care homes. This is important in case residents find themselves not being able to voice their preferences and wishes at a later date.

The document aims to enable discussions about such future care to take place between a resident, their family/other people important to them, and the caring team (GPs, nurses/ district nurses and care home staff). The document has some suggested questions that are useful to ask.

Wherever possible it is important to involve the resident, and the people who are important to them, in these discussions - even when a resident has dementia.

This is not a legal document. However, if in the future a decision regarding care needs to be made, the information in this document is available to decision makers.

Name of resident:

Date of birth:

GP's name:

Family member who is point of contact:

Name:

Address:

Postcode: Telephone Number:

Has a power of attorney(s) been appointed? Yes No

If 'yes', please provide details:

Name:

Address:

Postcode: Telephone Number:

Has an advance statement or other document outlining personal wishes already been written?

Yes No

Has an advance decision to refuse treatment (ADRT) been written? Yes No

Discussions in this document are based around the care the frail older person themselves would want to happen towards the end of life. It is about preparing for the worst, while hoping for the best. Such knowledge is collectively gathered and recorded in this document.

Do you (or, in the case of incapacity, your family member) have any particular wishes that you (or your family member) would want to achieve in the near future? If so, is there anything we can do to help with this?

In the event of a gradual decline in health, is there anything that worries you (or, your family member), or that you (or, your family member) dreads happening?

Are there any special wishes that you (or, your family member) would like us to know about when you (or, your family member) approach the end of life?

Do you (or, your family member) have a particular faith or belief system that is important to you (or them)? Would you like a priest/spiritual adviser to come and visit?

At the very end of life, where would you (or your family member) like to be cared for?

Is there any specific ritual/religious practice that you wish to happen following the death that you (or, your family member) would like to make known? For instance, funeral details, burial/cremation

Summary of any further discussion

Care professional leading the discussion:

Name:

Role:

Date:

Please list those present at discussion:

Name:

Relationship to resident:

Name:

Relationship to resident:

Name:

Relationship to resident:

Monthly 'Mapping Changes in Resident's Condition' chart

(Adapted from Macmillan 2004 – Foundations in Palliative Care)

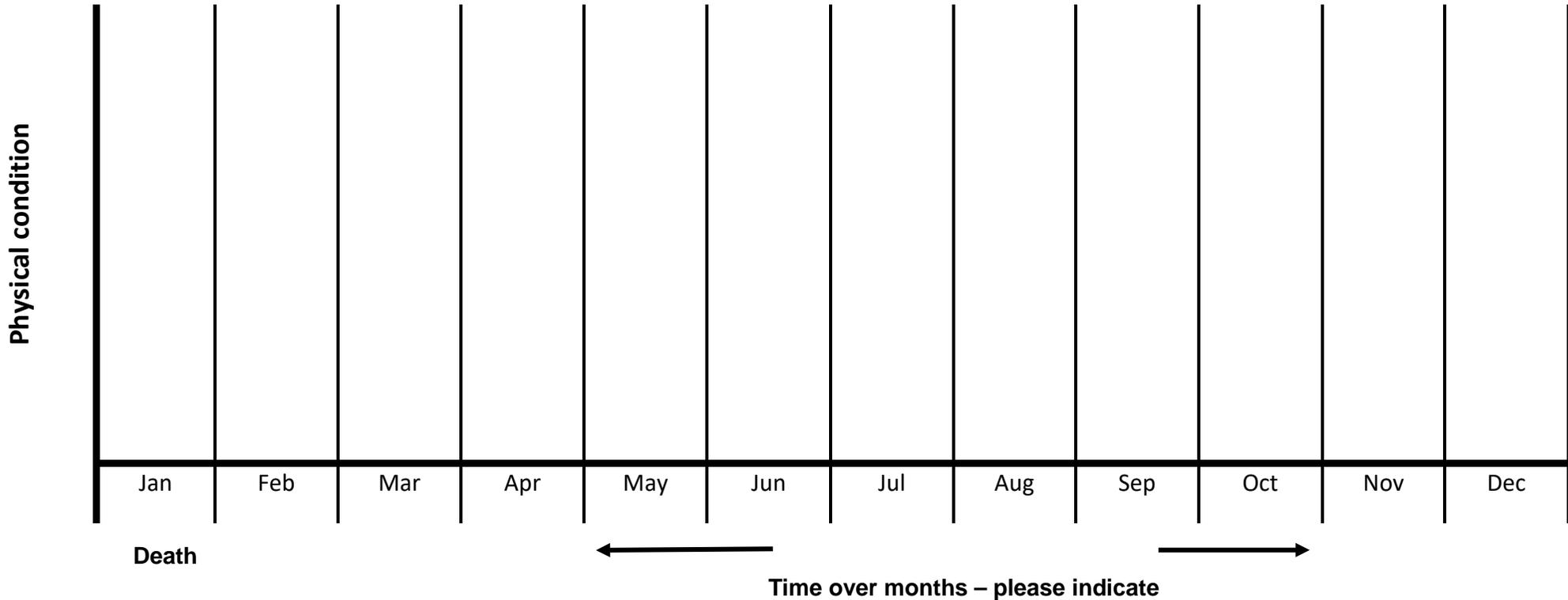
Resident's name:

Main Diagnosis:

Date tool commenced:

Use this graph at your **monthly** multi-disciplinary palliative care review meetings to plot change in the resident's condition.

Fit and well



(Copyright; Hockley et al., St Christopher's Hospice)

Resident name, age, DOA ¹	Diagnoses	Anticipated time to live [Y,M.W.D] ²	Doctor	DNACPR decision date ³	Future care plan discussion date ⁴	Problems/Concerns Assessments Communication with resident /family	SPC/ hospice /other specialists ⁵	Out of hours providers informed of EoL care date ⁶	POC at EoL discussion date ⁷	Last days of life documentation date ⁸	Actual POD/ date ⁹	Bereavement support necessary ¹⁰

1. Date of admission (DoA)
2. Anticipated time to live in years, months, weeks, days [Y,M,W,D]
3. Date when decision made not to attempt cardio-pulmonary resuscitation
4. Date when plans about future care first discussed
5. Specialist Palliative Care / hospice involvement +/- other specialists e.g. physio, social worker, dietitian etc

6. Date information re end-of-life (EoL) care sent to 'out of hours' providers
7. Place of care (PoC) at end of life (EoL) discussion + date
8. Date when documentation for assessment & management of last days of life commenced [or similar documentation]
9. Place of death (PoD)
10. Particular bereavement support for relative necessary? Y/N

Summary sheet of monthly multi-disciplinary palliative care review meetings using Palliative Care Register

Care home/ floor:

Total number of residents to be discussed:

Name of GPs present:

Date:

Names of staff present:

Name: Role:

Name: Role:

Name: Role:

Name: Role:

Number of residents reviewed	
Number of residents still to have 'Looking and Thinking Ahead' documentation completed	
Number of residents discussed with in-depth problems	

ACTION POINTS for specific residents with in-depth problems:

Resident name	Action to be taken by whom and by when	Outcome

Care Home Pain Assessment and Management Tool (with PAINAD scale)

To be completed on each resident: on admission if resident taking pain killers; if resident appears in pain; and always at six-monthly review

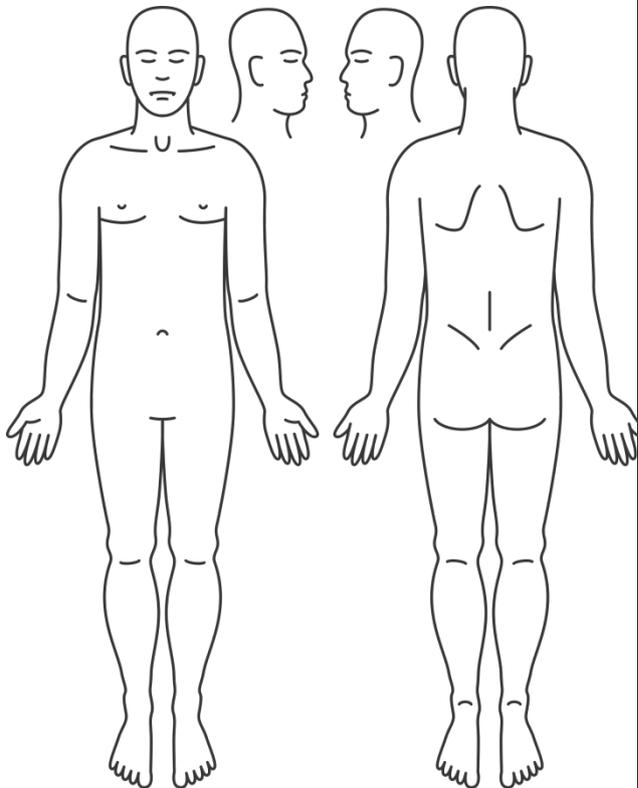
Name of care home:

Name of resident:

Date of admission:

Date of first assessment:

Current medications being taken by the resident



Pain intensity scale

If 0 out of 10 = no pain and 10 out of 10 = worst pain you have ever had in your whole life, what score out of 10 would you give the pain you currently have?

- 10** The worst pain you have ever had
- 9**
- 8** Very severe pain
- 7**
- 6** Severe pain
- 5**
- 4** Moderate pain
- 3**
- 2** Mild pain
- 1**
- 0** No pain

1 Where is or are your worst pain(s)? Please mark the site of pain on the body tool above left.

2 How bad is the pain on the intensity scale? Please tick the relevant box in the pain intensity tool above right.

3 How long has the pain been present?

4 Does anything make the pain worse?

5 Does anything make the pain better?

Pain Assessment in Advanced Dementia (PAINAD) scale

Use this assessment tool when a person is unable to accurately describe their pain (Volicer & Hurley [7])				
Items	0	1	2	Score
Breathing (independent of vocalisation)	<ul style="list-style-type: none"> Normal 	<ul style="list-style-type: none"> Occasional laboured breathing Short period of hyperventilation 	<ul style="list-style-type: none"> Noisy laboured breathing Long period of hyperventilation Cheyne-Stokes respirations 	
Negative vocalisation	<ul style="list-style-type: none"> None 	<ul style="list-style-type: none"> Occasional moan or groan Low-level speech with a negative or disapproving quality 	<ul style="list-style-type: none"> Repeated troubled calling out Loud moaning or groaning Crying 	
Facial expression	<ul style="list-style-type: none"> Smiling or inexpressive 	<ul style="list-style-type: none"> Sad Frightened Frown 	<ul style="list-style-type: none"> Facial grimacing 	
Body language	<ul style="list-style-type: none"> Relaxed 	<ul style="list-style-type: none"> Tense Distressed pacing Fidgeting 	<ul style="list-style-type: none"> Rigid Fists clenched Knees pulled up Pulling or pushing away Striking out. 	
Consolability	<ul style="list-style-type: none"> No need to console 	<ul style="list-style-type: none"> Distracted or reassured by voice or touch 	<ul style="list-style-type: none"> Unable to console, distract or reassure 	
TOTAL				
Total scores range from 0 to 10 (based on a scale of 0 to 2 for five items), with a higher score indicating more severe pain (0='no pain' to 10='severe pain'). A total score of 2 or more indicates pain and requires action.				
NB Once you have 'scored' the pain make sure you document the necessary management on the next page				

Definitions of some terms used in the PAINAD – please see Volicer & Hurley [7] for full explanation

Breathing: *'occasional laboured'* – episodic bursts of harsh/difficult respirations; *'short period of hyperventilation'* – intervals of rapid, deep breaths lasting a short period of time; *'noisy laboured'* – negative-sounding respirations on inspiration & expiration appearing strenuous which may be loud, gurgling or wheezing; *'long period of hyperventilation'* – excessive rate/depth of respirations lasting a long time; *'Cheyne-Stokes'* – waxing and waning of breathing from very deep to shallow respirations with periods of apnoea.

Negative Vocalisation: *'occasional moan/groan'* – mournful/murmuring sounds, wails or laments – groaning is involuntary often abruptly beginning & ending; *'low-level speech with a negative or disapproving quality'* – muttering, mumbling, whining, grumbling or swearing; *'repeated troubled calling out'* – repetitive words in an anxious, uneasy or distressed tone; *'loud moaning or groaning'* – mournful/murmuring sounds, wails or laments in a louder volume than usual often abruptly beginning or ending; *'crying'* – emotion accompanied by tears which can be sobbing or quiet weeping

Facial Expression: *'sad'* – unhappy/sorrowful/dejected look; *'frightened'* – a look of fear/alarm or heightened anxiety; *'frown'* – increased facial wrinkling in forehead or around mouth; *'facial grimacing'* – distorted/distressed look.

Body Language: lying still and afraid to move, or very restless

Consolability: able to be reassured

Assessment checklist for the Management of the Last Days of Life & Process of Dying

Care home/floor:

Resident name:

Checklist	Date
<p>1. Team discussion/recognition that the resident may now be dying. The following things may be seen:</p> <ul style="list-style-type: none"> • Repeated infections • Weight loss • Lack of interest in life • Spending more time asleep during day than awake • Reduced food/fluid intake • Reversible treatments considered and deemed inappropriate 	
<p>2. Senior and/or GP speak with family/next of kin</p> <ul style="list-style-type: none"> • Dignity and comfort as the goal of care with death in the care home • Decision regarding 'do not attempt cardio-pulmonary resuscitation' made 	
<p>3. Anticipatory medication for symptoms in last days of life prescribed and available in care home</p> <ul style="list-style-type: none"> • Appropriate anticipatory medication (sub-cutaneous or suppositories) for anxiety, respiratory secretions. and/or pain prescribed • All unnecessary medication discontinued 	
On-going care [detail in care plan]	
<p>4. Hydration</p> <ul style="list-style-type: none"> • Resident encouraged to take fluids, ice cream, jelly by mouth as able (if aspirating consider crushed ice in gauze to suck) • Regular mouth care – involve family as appropriate • In rare circumstances sub-cutaneous fluids may be appropriate after discussion with GP/palliative care team 	
<p>5. Regular 2 hourly care being carried out with regard to:</p> <ul style="list-style-type: none"> • restlessness • pain • noisy breathing • turning to prevent stiffness other 	
<p>6. Spiritual needs attended to whether Christian, Muslim, Jewish and any other faiths (see resource folder for information)</p> <ul style="list-style-type: none"> • Christian – priest/chaplain called especially if in the past the resident went to church • Muslim – family generally very involved and often want funeral within 24 hours of death • Jewish – family generally inform Rabbi – special attention to last offices 	
<p>7. Psycho-social spiritual support</p> <ul style="list-style-type: none"> • Resident – sensory input (music, scents, touch, being read to, also: <ul style="list-style-type: none"> • Not to be left alone in final process of dying (see overleaf). • Talk to resident i.e. when turning and re-positioning. Hearing is active until moment of death. • Many residents are aware that they are dying often using symbolic language. Detail in care plan. Do not be afraid to talk about dying if they make reference to it. • Family – continual communication about process of dying prepare them for being present at time of death (see 'Process of Dying' diagram) 	
<p>8. At death</p> <ul style="list-style-type: none"> • Comfort family/next of kin • Inform GP • Communicate death with all staff and other residents • Organise day/time for team 'reflective de-brief' 	

Reflective debriefing tool

Initial of resident:

Date of reflection:

Reflective debriefing is the process whereby clinical practice can be re-examined to foster the development of critical thinking and learning for improved practice. The process is on-going with each debriefing and should be viewed as an aid to lifelong learning rather than a single process.

1. Describe the person/event.

For no more than five minutes, encourage all staff to recall their memory about the person or event – such as:

- Person: What were they like, what did they like to do? Did they have family? Who was important to them? What did they like/dislike? Were they humorous/serious/sad/angry? What was their perspective on what was happening? Did they have fears/anxieties?
- Event: What was the event? Who was involved?

2. What happened leading up to the death/event?

Describe what happened for individuals on the various shifts that led up to the death/event

3. How do staff feel things went? What went well? What didn't go so well? How did people feel?

Both positive and negative feelings should be described and owned. Feelings can be a useful guide to how learning is progressing so whilst it is important to be honest it is also important to respect other peoples feelings. Look at the decisions that were made – this will help you to understand what else could/could not have been done. Opinions of others will help this process. Remember to reflect on what was hoped and planned for, the original aims and objectives i.e. in the event of death in the care home:

- Was the Documentation for the Assessment/Management of the Last Days used?
- Were anticipatory drugs in place?
- Were symptoms controlled?
- Were family supported and informed?
- Were spiritual needs addressed?
- Were they in the place of their choice?
- Was a decision made that cardio-pulmonary resuscitation was inappropriate if heart stopped suddenly?
- Was an advance care plan completed?

4. What could have been done differently?

Existing knowledge can be built on by theorising about what could have been done differently. In order for this to be, effective critical thinking in a safe learning environment is essential with a 'no blame' attitude.

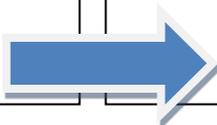
5. What do we need to change as a result of this reflection?

Key learning points can be listed and any action plans needed to enhance learning/more appropriate care. This might be a change in or re-writing of a policy, further chats with GP/nurse specialist in order that in the future the problem being discussed does not occur again, or it may highlight a need for training. It is essential that these learning points are not just logged but acted on.

Each reflection can inform practice and should be used not only as a building block to learning but as a celebration of good practice. Reflection is not a passive contemplation but an active, deliberate process that requires commitment, energy and a willingness to learn as a team

1. Pen portrait of person or event

2. What happened leading up to the death?



3b. What didn't go so well?

3a. How do staff feel things went? What went well?



4. What could we have been done differently?

5. What do we need to change as a result of this reflection?



Data to be collected from records following a death of a resident in the care home

Initials	Gender	DOA ¹	DOD ²	Current diagnoses	DNACPR ? ³	Care Discussion ? ⁴	Last days of life tool ⁵		Hospital death only ⁸			Type of death ⁹	
							Tool used?	Start date	Hospital Admission ⁶	Place of death ⁷	Admission time		Person req. ⁸

Guidance Notes:

1. Date of admission
2. Date of death
3. Documented evidence of DNACPR?
4. Documented evidence of future care discussion?
5. Use of tool for last days of life and date tool commenced
6. Number of hospital admissions in last month of life
7. Place of death: care home, hospice, hospital (if recently discharged from hospital state no. of days prior to death)
8. Hospital death only: please complete time of admission and who requested admission
9. D = dwindling – slow deterioration with loss of weight over a matter of weeks/months; S = sudden (i.e. heart attack in dining room; or found dead in bed at night); A = after ‘acute’ episode – ‘unexpected death’ with deterioration over a few days (i.e. extension of stroke; fractured femur); T = diagnosed terminal condition – cancer, Parkinson’s