

Appendix 1. Do not attempt Cardiopulmonary Resuscitation(DNACPR)

DNACPR can be used to prevent futile or unwanted CPR attempts. CPR is a physically traumatic treatment for any who receive it, and emotionally traumatic for families and carers who witness it. There can be significant consequences regardless of the outcome.

As with any medical intervention, patients do not have a 'right' to CPR. However it can be highly emotive matter, and as such requires a significant amount of sensitivity.

The DNACPR framework can be considered in logical steps. The two important questions are:

- Can a cardiac or respiratory arrest be anticipated?
- Would CPR have a medically successful outcome, or not?

Can a cardiopulmonary arrest be anticipated?

Any death, particularly a perceived 'sudden death', can be viewed as a situation for potential resuscitation by emergency services. In cases of end of life care, where death is anticipated, allowing a natural death must be considered.

The appropriateness of CPR should be considered in advance of a cardiorespiratory arrest, which by its nature, occurs without warning.

Would CPR have a medically successful outcome, or not?

This is a medical decision based upon likelihood of success. Successful CPR is not just the initial return of spontaneous respiration and cardiac rhythm, but the prolongation of life.

It may help to consider whether the patient would be a candidate for intensive care (I would un-delete this sentence). If not, then this would lend weight to a DNACPR decision.

When considering likelihood of CPR success, influential factors include; age, the medical condition(s) the patient is suffering from, where they are on their disease trajectory, and the availability of resuscitation equipment and personnel to undertake CPR.

Where there is genuine doubt about the chance of a medically successful outcome, seek advice. The Scottish DNACPR framework allows the patient to request a second opinion. This should be supplied by someone who knows the patient. It may be another GP in the practice or another member of the practice team; or it may be a consultant or senior nurse practitioner. The patient may agree with your view - but want to cross-check it, or simply need time to really take it in.

Patients suffering from a life-limiting illness where cardiac or respiratory arrest is anticipated, for whom CPR would realistically have a medically successful outcome, must have the *opportunity to discuss* their wishes regarding CPR.

If, however, it is felt that CPR would realistically not have a medically successful outcome, then it should not be offered as a treatment option. This decision should then be sensitively conveyed to the patient by suitably skilled health care professionals and (with the patients permission) their family and loved ones.

Once a decision has been reached this should be clearly documented and communicated. The decision must then be entered onto the KIS so that providers of unscheduled care know about it. The Scottish Ambulance Service is able to accept a DNACPR decision which has been logged on the KIS.

Resuscitation decisions should be reviewed whenever the patient's circumstances change. This is particularly important after discharge from hospital as the DNACPR decision may have been made hastily during an admission process whilst the patient was acutely unwell.

If the patient lacks capacity, and if resuscitation is likely to have a successful outcome, then the patients legal representative e.g. welfare Power of Attorney, or Guardian, should be involved in the decision-making process. Unless a relative has a legal status, they should not be burdened with decision-making regarding DNACPR.

A useful patient information leaflet explains everything about DNACPR in detail:
<http://www.scotland.gov.uk/Resource/Doc/924/0098811.pdf>

Appendix 2. - An ACP for a patient with Dementia

Good practice for people with dementia:

- Encourage early discussion about future care
- Help the person and their carers to develop an Advanced Care Plan
- Promote the appointment of a Welfare Power of Attorney
- Always assess capacity and, where possible, include the patient in the decision-making process
- Make appropriate use of Part V of the Adults with Incapacity Act (2000)
- Adhere to the principles of the Act when considering content of a care-plan
- Involve all relevant parties in development of the plan
- Include preferences for palliative and end of life care
- Take account of any advanced directive
- Document and share the plan

Where a patient lacks capacity, Part V of the Adults with Incapacity Act must be used, and the appropriate certificate completed

A certificate can be issued for a three-year period, although at least annual review is encouraged.

The treatment plan attached to the completed certificate should cover all necessary interventions, including medical, nursing and dental treatments and must be discussed and agreed with any appointed proxy. It may include a plan for managing their long term conditions, what to do in the event of deterioration, and should include discussion about palliative and end of life care.

It should not authorise an intervention that would normally require signed consent from the patient.

Any appointed Attorney or Guardian must be included in the process as well as members of the multidisciplinary team.

Decisions, including those relating to withdrawal of treatments and resuscitation, should be clearly recorded and communicated to all relevant members of the care team.

Anticipatory care planning may include:

- managing physical symptoms and changes in behaviour;
- managing complications such as pneumonia, febrile episodes and swallowing and eating problems;
- avoiding admission to hospital; and/or facilitating early discharge if admitted to hospital;
- see [Box 3](#) for other ACP information which could be added

The following template may be useful for checking all areas have been discussed while preparing an ACP for a patient with dementia. Note that

information would need to be cut and pasted onto a KIS, as these do not (at the time of writing) have the capacity to support attachments.

Is patient on the dementia register?	YES	NO
Diagnosis: Alzheimer's, vascular, mixed, Lewy Body, frontotemporal, or "other"		
Stage: early, mid, late, palliative		
Chronic physical illness? e.g. cardiac, respiratory, or neurological disease		
Physical disease Care Plan?	YES	NO
Preferred place of treatment: home, care home, hospital		
DNACPR in place?	YES	NO
Capacity assessed?	YES	NO
AWI part V cert in place?	YES	NO
Power of Attorney?	YES	NO
Advance care plan made by patient?	YES	NO
Risk assessment: e.g. risk of falls, pain level, recurrent sepsis, medication compliance, hydration/nutrition, continence, behaviour/mood change		
Carer: Cohabiting, near relative, professional, institution		

[We wish to thank Dr Gillian Mclean, Consultant Psychiatrist, Forth Valley, for help with this section of the module. She also provided a poster which is used by her team, to encourage patients to think about an ACP at an early stage. This is reproduced on the next page.]

The Future - Thinking Ahead :

Advance Care Planning for people who have been diagnosed with dementia in Forth Valley

What is Advance Care Planning ?

Advance Care Planning is a series of steps you can take now to plan for your future when you may not have the capacity to make some informed choices. It includes decisions about care, treatments and money and makes sure that everyone involved in looking after someone with dementia, including doctors, care workers, family carers and the person themselves thinks about, discusses and then record the person's wishes regarding their ongoing care.

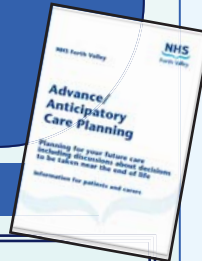
How will this help you ?

- ◆ To explore your options
- ◆ Identify your wishes and preferences
- ◆ Refuse specific treatments and interventions if you wish to
- ◆ Ask someone to be your attorney and speak for you
- ◆ Let your family and healthcare team know what your wishes are
- ◆ Build trusting relationships with your care team

What are the benefits ?

- ◆ A voice in your care even if you are unable to speak for yourself
- ◆ Peace of mind you have recorded the care you want and the interventions you don't want
- ◆ Family and friends are aware of the decisions you have made

How to start your care plan



THINK— about what is right for you:

- ◆ What is important to you such as where you want to stay
- ◆ What are your goals
- ◆ End of life wishes including interventions you may or may not want

LEARN – about who and what is available:

- ◆ Resources and people to give support to you and your carers
- ◆ Treatment and care options
- ◆ Legal and money matters

CHOOSE – substitute decision makers:

- ◆ An attorney who can make plans for financial, property and personal matters
- ◆ An advocate to help you understand and say what you want

TALK – about your wishes with:

- ◆ Family, carers and loved ones
- ◆ Attorney, advocate, and solicitor
- ◆ GP, nurses, social worker, liaison workers

RECORD – and share your wishes:

- ◆ A hand held paper record for you and your family
- ◆ Electronically with GP – Emergency and / or Palliative care summary
- ◆ Review when your situation changes but at least yearly

What support is available ?

Local Authority



- ◆ Community care assessment and services
- ◆ Housing and adaptations if required
- ◆ Day care, respite and residential support
- ◆ Carer information and support groups

Health and Wellbeing Services



- ◆ GP, Primary Care Team and Social Services
- ◆ Community Mental Health Team
- ◆ Alzheimer Nurse Consultant
- ◆ Psychiatric Liaison Nurse Specialists
- ◆ Dementia Champions and Ambassadors

Legal and Information Services



- ◆ Powers of Attorney
- ◆ Benefits information and advice
- ◆ Money and legal matters
- ◆ Carers support and advice

Useful Information



Contact Macmillan for a free information pack which is full of advice to support you in making an advance care plan



The Princess Royal Trust for Carers
<http://www.carers.org/local-service/falkirk>



Standards of Care for Dementia in Scotland
www.scotland.gov.uk/Resource/Doc/350188/0117212.pdf



Anticipatory Care Planning frequently asked questions
www.scotland.gov.uk/Resource/Doc/309277/0097422.pdf

Appendix 4. Advance Directives.

Information on advanced directives is given here, but not mentioned elsewhere in the module, to emphasise that an advanced directive and an ACP are completely different entities. An ACP is a plan put together by the medical team (with advice from the patient) to plan future care needs, and quite correctly it changes over time. An advanced directive is a legal document. It is drawn up by the patient, possibly with the help of a solicitor, and remains unchanged, unless the patient decides to make changes to it.

Having stated the differences between ACPs and advanced directives above, it is obviously important that the presence of an advanced directive is mentioned in an ACP, as this should clearly describe the patient's wishes.

Introduction

Advance directives are known in lay terms as "Living Wills" (although strictly speaking a living will indicates a person's wishes in their last 6 months of life only). They are used to indicate a person's specific wish to refuse all or certain forms of medical treatment, and the circumstances under which these wishes would apply. Advance Directives are considered legally binding on the treating medical team, assuming that they are valid and applicable to the circumstances that then arise.

Currently an estimated 1 million people have an advance directive in the UK. They are most commonly used by Jehovah's Witnesses to refuse blood and blood products in advance - but they are increasingly being completed by patients with incurable diagnoses such as degenerative neurological conditions, HIV, terminal cancer, and early dementia.

Purpose

It is an established principle in UK law that a competent person should be actively involved in decisions regarding his or her health care, including the right to refuse treatment, even if this may be life-saving. Provided that the refusal of consent to such treatment is valid (made on the basis of appropriate information, on a voluntary basis, with the capacity to do so) it should be upheld, even if the decision appears illogical or irrational. Treating a competent patient against their wishes, even if deemed to be in their "best interests", could constitute assault by the treating doctor.

Legality

They are legally binding in the UK provided that:

- They have been validly written
- Circumstances that subsequently arise are applicable to those described in the advanced directive
- the patient must have given informed and voluntary consent to the advanced directive when it was prepared, and have had the capacity to do this

Provided that these conditions are met, the directive will be legally binding on doctors, under the Mental Capacity Act 2005 in England and Wales, and under common law in Scotland (they were omitted from the equivalent piece of Scottish legislation, the Adults with Incapacity Act 2000).

Competency Assessments

Ideally any advanced directive completed by a patient should be accompanied by a statement of competency completed by a healthcare professional at the time the directive was written. As GPs we may be asked to provide this. Often the situation is straightforward and a statement can be issued easily. For those patients whose capacity is in doubt, seek advice, possibly from a psychiatrist.

Limitations

Their main purpose is to allow prospective refusal of treatments, although they cannot be used to refuse basic care (such as mouth care, basic hygiene). They can also be used to document treatment requests, although these requests will only be adhered to if they are considered clinically appropriate. They cannot be used to request "treatments" that are currently illegal under UK law, such as physician-assisted suicide or euthanasia.

An advanced directive can be revoked by the patient at any time - provided they are competent to do so, and (rarely) by the medical team if there is grounds to believe that the reason for the directive has altered e.g. change of religion..

Storage, and proxies

Ideally copies of the advanced directive would be stored in several places: the GP records, any relevant hospital records, with the next of kin, with our proxy (if we have one), and perhaps with a solicitor.

A proxy decision-maker can be nominated, but our own wishes can never be accurately predicted. A proxy will often make decisions on what they consider to be in our best interests, rather than what we would necessarily have wished for ourselves. Some studies suggest that we underestimate the level of active treatment we would actually wish.

Appendix 5 – screenshots from the KIS (EMIS)

EMIS PCS - LAN Edition (Antonine Medical Practice)

File Help

Modules Internet NPRT

F8 - Save Z - Cancel
B - Brief Summary # - Fit Note

Consultation Mode - On 22/10/2014

Heading

P - Problem
H - History
E - Examination
Y - Family History
O - Social
C - Comment
L - Result
M - Medication
F - Follow up
Q - Test Request
R - New Referral
G - Allergy
V - Referral Activity
8 - KIS

Quick History: Most Recent

16 Oct 2014
(First) Problem
History
Examination
Comment

19 Aug 2014
History

Temp overnight, chesty cough. O/E P70. T38.1, rr15, creps R lung base-difficult to examine due to body habitus. abdo soft, non tender, urine looks normal. Legs no different from her usual. AB Px for LRTI. Amoxicillin 500mg TID 7d. R/V if further concerns/sympt. Discussion re her daughter who has brain tumour & has come to see her for holiday. Patient annoyed at her husband for phoning us today-says does not like to bother us-d/w her that is important phone for us to r/v if feeling unwell

Dr Amy Leckie at House Visit (Day)

Dr Peter McCalister @ Antonine Medical Practice (14813) (10.253.162.137)

<Ctrl> to activate Patient Summary (right hand side) NUM OVR Wed 22 Oct 2014 10:28 Dr Peter McCalister @ Antonine Medical Practice (14813) (10.253.162.137)

10:28
22/10/2014

KIS Data Entry

0 - Consent | 1 - Demographics | 2 - Current Situation | 3 - Care & Support | 4 - Resuscitation & Preferred Place Of Care | 5 - Palliative Care

KIS Upload Decision

☒ Send a Key Information Summary for this patient
☐ Do Not Send a Key Information Summary for this patient

Assigned Date: 22/10/2014

Patient Consent

Consent for key information summary upload	Assigned Date	Notes
<input type="checkbox"/> Vulnerable Person	04/06/2014	Date not Uploaded to KIS
<input type="checkbox"/> Risk to Self	22/10/2014	
<input type="checkbox"/> Risk to Others	22/10/2014	
<input type="checkbox"/> Legal Requirement	22/10/2014	

Special Notes (shared with ePCS)

☒ Apply Special Note

This very obese lady has AF, obesity hypoventilation leading to cyanosis, post-polio syndrome, and chronic oedema. She is immobile without carers and a hoist. However is comfortable on home oxygen and sats were 91% in June 2014. She is likely to refuse hospital admission and has the capacity to make that decision. Her caring husband is tired but coping. I suspect she will only call in extremis and a clinical judgement will be difficult as to admit or not - she does tend to respond to antibiotics for chest infections which have caused worsening cyanosis in the past. DNACPR in place. KIS review 12.8.14

☐ Apply Expiry Date: Special Note will not expire

(608 of 2048 characters used)

KIS Review Date (Practice Use Only)

☒ KIS Review Date: 05/06/2015

OK Cancel

The “special notes” box is to be used for all freetext information

The practice expiry date is only to aid practice admin: the KIS will not expire after this date

KIS Data Entry

0: Consent | 1: Demographics | 2: Current Situation | 3: Care & Support | 4: Resuscitation & Preferred Place Of Care | 5: Palliative Care

Medical History

Main Diagnosis

23/10/2005	Atrial fibrillation
23/10/2005	Congestive cardiac failure
23/10/2005	Cellulitis NOS

Self Management Plan

Anticipatory Care Plan

Has anticipatory care plan: [dropdown] | Date: [04/06/2014] | Text: keep at home unless there is no other option - she would prefer it this way

Single Shared Assessment (SSA)

[None] | Date: [22/10/2014] | Text: []

Oxygen

Home oxygen supply - concentrator: [dropdown] | Date: [04/06/2014] | Text: []

Additional drugs available at home (shared with ePCS)

[None] | Date: [22/10/2014] | Text: []

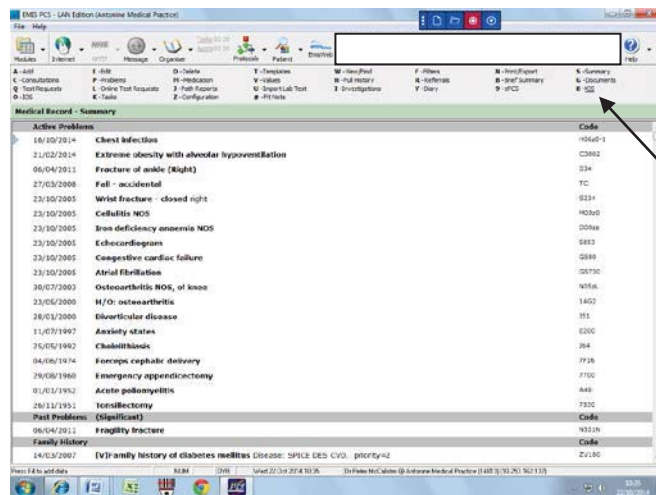
Catheter and Continence Equipment at home (shared with ePCS)

[None] | Date: [22/10/2014] | Text: []

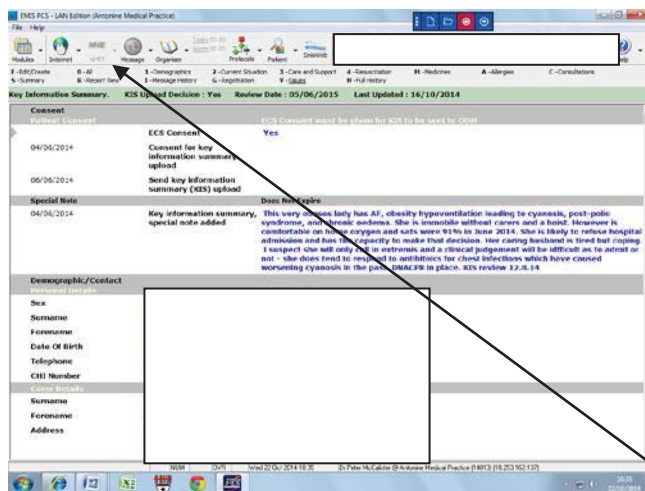
OK Cancel

To actively create an ACP as requested by the QOF, this box needs to be selected from the dropdown menu, though the freetext box to the right should have minimal (or no) text. All freetext should be in the “special notes” box shown on the previous page, to make reading easier for those in OOH and A&E.

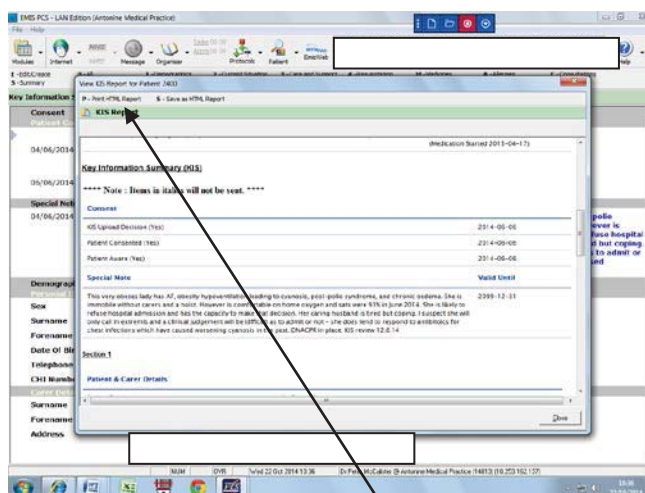
Printing a KIS, for a nursing home or the patient's home:



In EMIS, the “medical record” tab contains a KIS tab: clicking on this opens the screen shown below



In this view of the KIS, there is a tab which allows a “report” to be created. Clicking on this leads to the next screen, where there is a print option



Click here to print the KIS.