Palliative care in Barnsley

The end in Light – BMA News May 2016

Our ethos is to add life to days rather than days to life!

Palliative Care in Barnsley

Dr. Rachel Vedder

Consultant in Palliative Medicine

Janet Owen

Team Leader Macmillan Community Specialist Palliative Care Team, Clinical Lead for EOLC

Katie Yockney

Practice Educator, EOLC Team

Outline

- Palliative care and End of Life Care (EOLC)
- Specialist level palliative care
- Local services

- Case to illustrate

- Advanced Care Planning, DNACPR

Palliative Care

Palliative care is provided by three categories of health and social care professionals:

- Those providing the day-to-day care to patients and carers in their homes and in hospitals
- Those providing disease specific specialist care for life-limiting illness
- Those who specialise in palliative care (consultants in palliative medicine and clinical nurse specialists in palliative care, for example)

Core level Palliative Care

Those providing day-to-day care should be able to:

- Assess the care needs of each patient and their families across the domains of physical, psychological, social spiritual and information needs

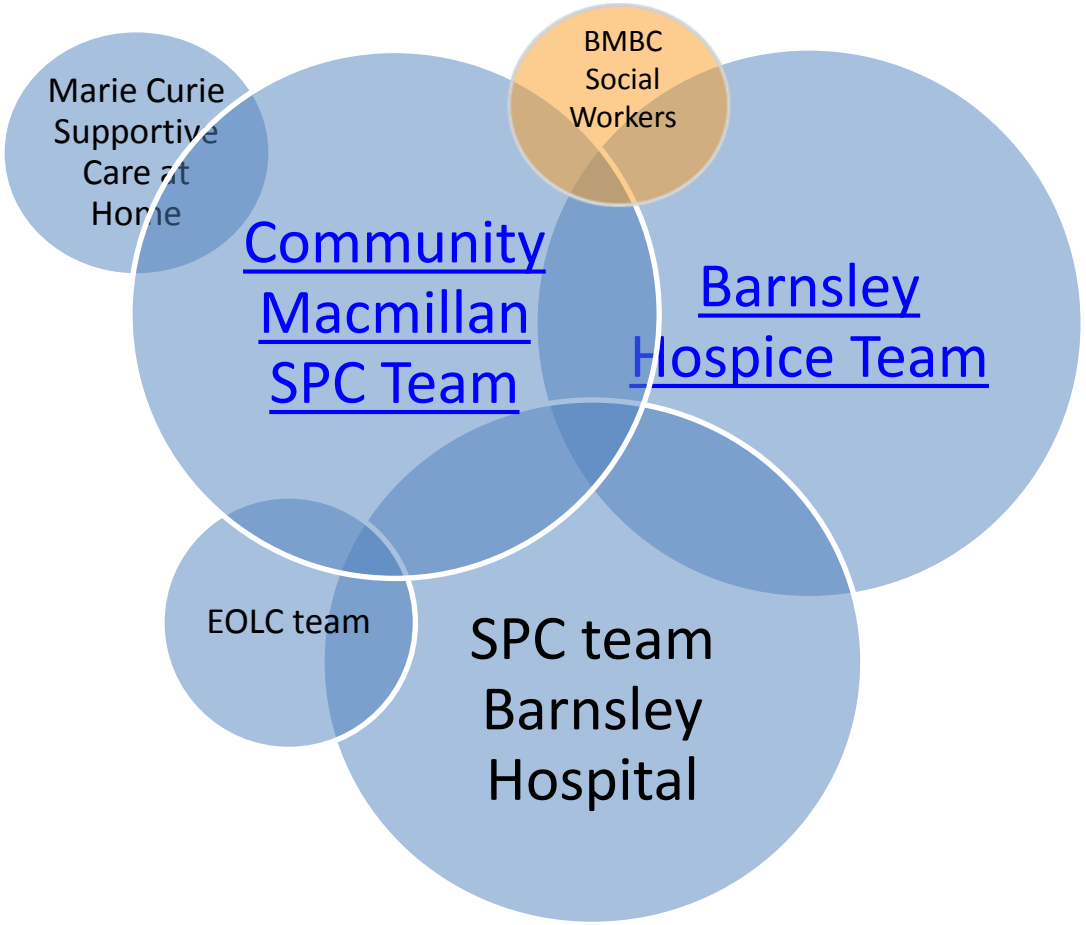
- Meet those needs within the limits of their knowledge, skills, competence in palliative care

- Know when to seek advice from or refer to specialist palliative care services

Specialist Level Palliative Care

- Complex cases
  - Unresolved complex needs
    - Complicated symptoms, difficult family situations, ethical questions regarding treatment decisions
    - Cannot be fully met by the current caring team
- Holistic person-centred care and shared decision-making
- Multi-disciplinary teams
- Facilitating communication between teams in health and social care, effective joint working
- Palliative care education and input into development of systems and services to support generalist palliative care

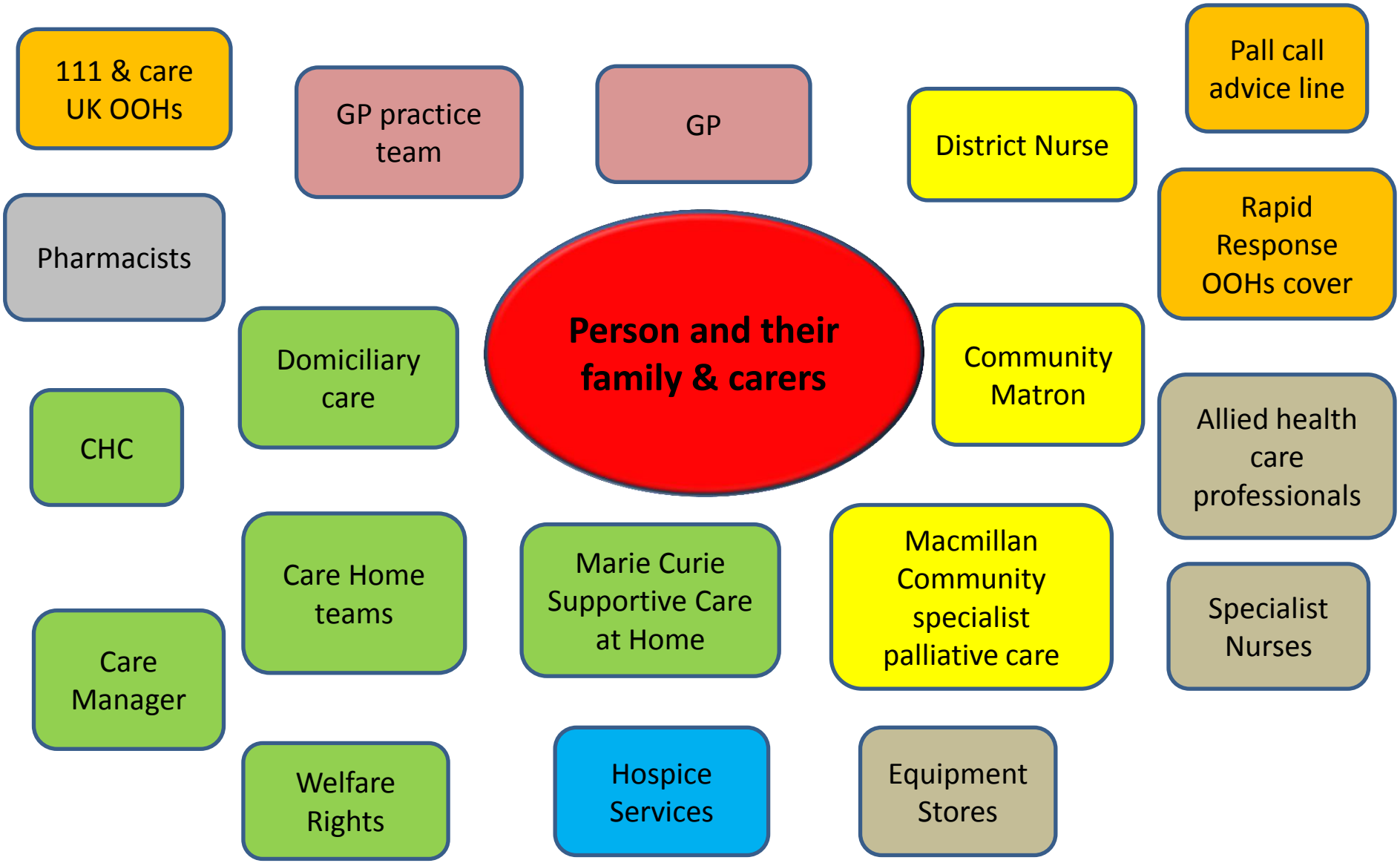
Barnsley Specialist Level Palliative Care Team



Community Macmillan Specialist Palliative Care Team


Barnsley Hospice
Consultant led 10 bedded in-patient unit
Family team – social worker, discharge coordinator, family support worker, chaplaincy/spiritual support, bereavement
Daycentre services 3 days of the week – for patients and carers
Palliative Medicine OPC and home visits Hospital and Community palliative care teams Specialist MDTs
Counselling service OP, IP and domiciliary
Lymphoedema service OP and domiciliary
Complementary therapy service, OP, IP and domiciliary
PallCall – 24hr palliative care telephone advice line

Community services palliative/end of life care



Key core services providing end of life care

GP	The GP has overall responsibility for care at the end of life. The GP will work with the wider team to ensure medical, emotional, social and spiritual needs are supported and care is coordinated
District Nurse	The district nurse will visit and provide care according to individual needs. They are usually the key worker for last days of life care in their own homes and residential care homes. They will liaise with other members of SWYFT community services.
Community Matron	Will provide case management for those with more complex needs e.g. polypharmacy, multiple comorbidities, repeated hospital admissions and may act as the key worker to co-ordinate care. They will liaise with other members of SWYFT community services.
Rapid Response Out of hours cover	Service provides out of hours district nursing from 4.45pm to 8.45am. This service is available for patients/carers to call for support advice or to request a visit to support their end of life/last days of life care as well as providing already planned visits.
111 & Out of hours GP services	It is important that out of hours services understand the care plans and preferences of palliative/end of life patients. To aid communication a palliative care handover form should be faxed in advance.
Social care	To arrange packages of social care e.g. domiciliary care or care home support, referrals should be made to BMBC Central Access Team.
CHC	CHC will provide continuing healthcare funding where appropriate in the last weeks of life, a fast track application can be sent.

Services specifically for palliative/end of life care

Specialist palliative care	Community Macmillan SPC Team / Barnsley Hospice / Hospital SPC Team
Marie Curie Supportive care at home	Practical, emotional and physical support provided to patients and carers 7 days a week for those with advance life threatening illness in the last days of life or for respite. A significant part of the service is providing night time 10pm – 7am visits. Urgent care can be provided in addition to social care provision or as a stand alone package. This is led by the nurse key worker. The service includes HCA and 3 qualified nurses. Referrals made from health care professionals
Macmillan Welfare Rights	This service will provide benefits advice for those with palliative/end of life care needs
Drug pharmacist stockist scheme	Certain pharmacists are part of a scheme where they always stock key palliative drugs

Specialist Palliative Care Team Referral

- For patients with progressive life-limiting illness, and their families, with complex needs :

  Uncontrolled or complicated symptoms
  Emotional or behavioural difficulties relating to the disease
  Complex social issues involving family, children and carers
  Difficult decision around withholding or withdrawing treatment
  Complex last days of life care

- (Needs link to referral form on website)
- Face to face services 9am-5pm 7 days a week
- 24/7 Pallcall advice line OOH can be used by patients and families as well as health and social care professionals – 01226 244 244

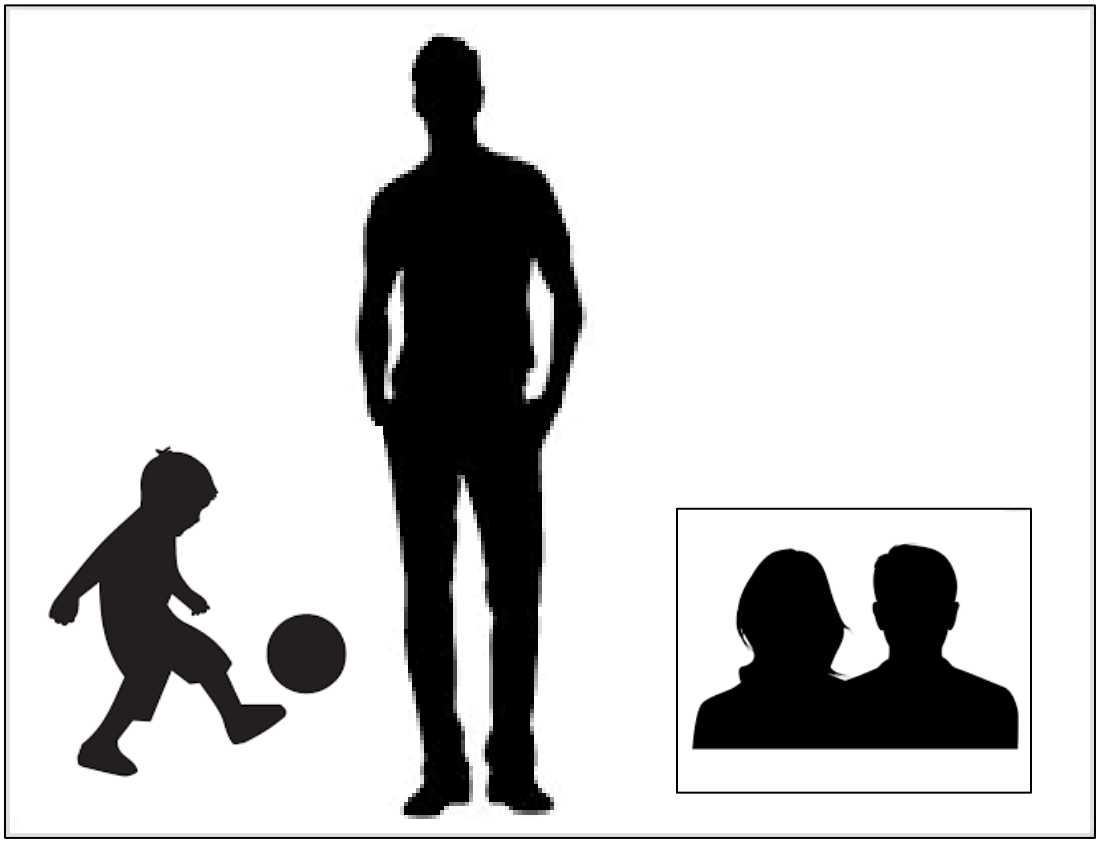
Key contact numbers for palliative and end of life care

Community service	Contact details	Referral
District nurses	01226 644575 7 days a week 8.45am - 4.45pm	Either telephone or Systmone
Rapid Response Out of hours DN cover	07747 794698 4.45pm – 8.45am	Telephone
Macmillan community specialist palliative care	01226 644755 9am-5pm Mon – Fri 01226 644575 9am-5pm Sat/Sun	Fax SPC Referral form or telephone contact to discuss
Marie Curie Supportive care at home	01226 644750 office hour Mon – Fri 9am -5pm Weekends on call service leave a message	Telephone
Community Matron	01226 644575 7 days a week 8.45am – 4.45pm	Either telephone or systmone
Care Manager – Central Access Team	01226 773300	Telephone for a referral form
Welfare Rights	01226 772310	Referral form
Continuing Healthcare	01302 566012	Referral form
Pall call Advice Line for out of hours Specialist palliative care advice	01226 244244 Out of hours	Telephone advice
Hospice	01226 244244	Fax SPC Referral form or telephone contact to discuss
Pharmacists - Out of hours	Stockists of palliative care medication See list on Barnsley end of life care website or in My Care Plan	

Levels of intervention

- **Level 1** Sign-posting or telephone advice for other professionals
- **Level 2** A one off home visit to support the generalist to plan management or care or to assess needs
- **Level 3** Short term complex specialist management – often alongside other primary care team members
- **Level 4** On going specialist support for those with complex needs – as a key worker or alongside others eg DN or community matron

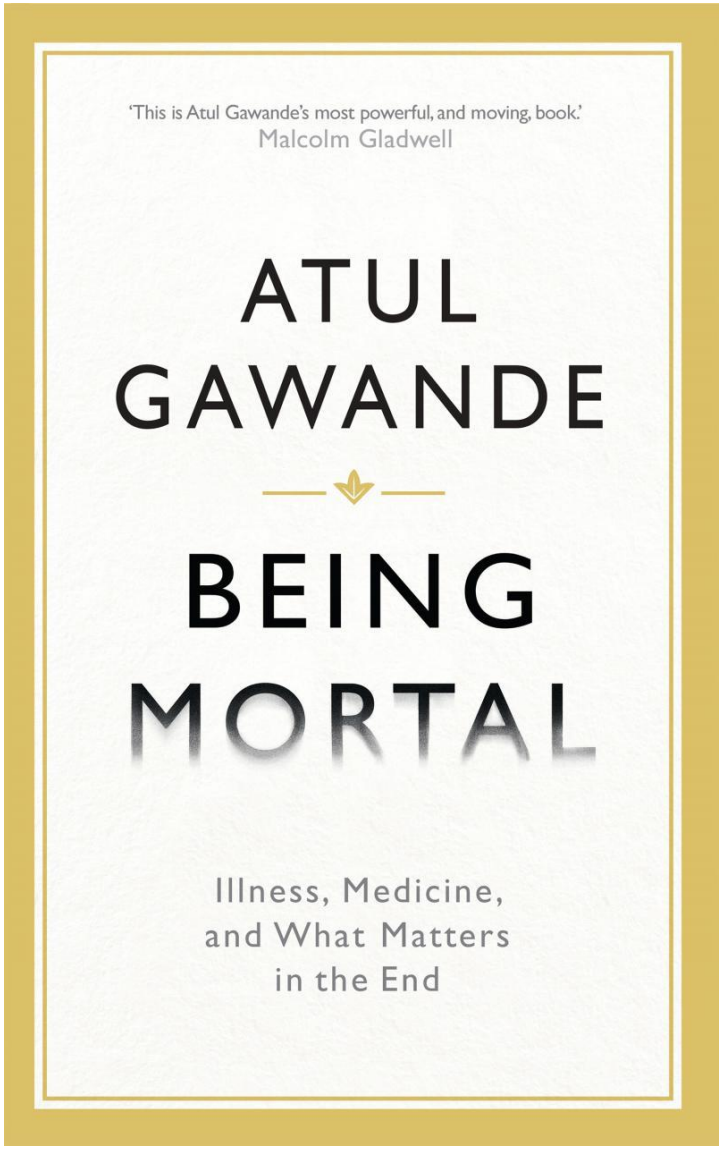
Amy . . . a stylish young mother and beauty therapist



Amy's last year . . .

Amy . . .

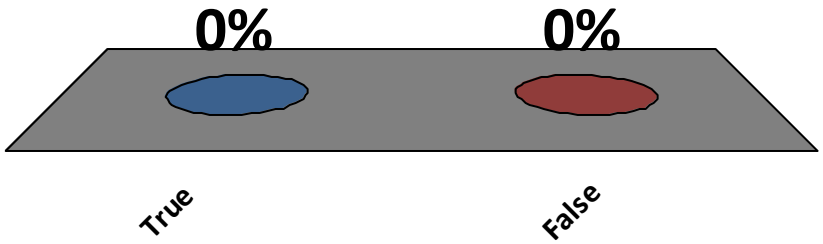
. . . a fierce determination to hold on to life and do normal things until the end


'This is Atul Gawande's most powerful, and moving, book.'
Malcolm Gladwell
ATUL
GAWANDE
BEING
MORTAL
Illness, Medicine,
and What Matters
in the End

Advanced Care Planning (ACP)

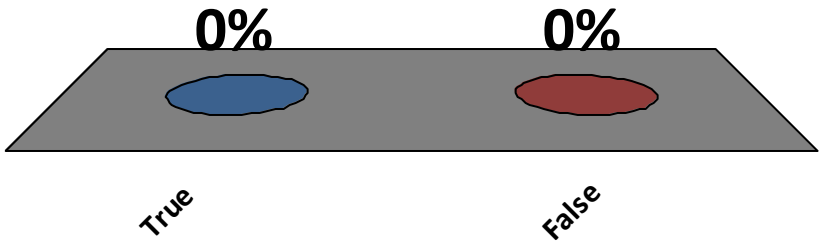
1. An Advanced Care Plan can be completed for individual who lacks capacity

A. True
B. False



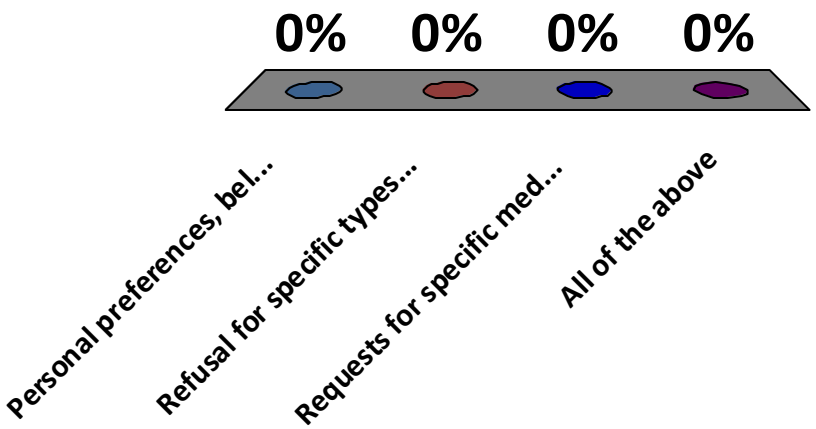
2. The GP should be informed if someone has completed an advanced care plan . .

A. True
B. False



3. What is in an **Advance Statement?**

A. Personal preferences, beliefs and wishes
B. Refusal for specific types of medical treatment
C. Requests for specific medical intervention
D. All of the above

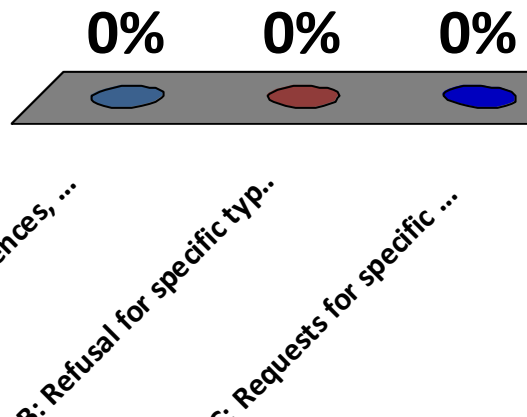


4. What is an **Advance Decision?**

A: Personal preferences, beliefs and wishes

B: Refusal for specific types of medical treatment

C: Requests for specific medical interventions



5. An Advanced Decision can enable a person to . . .

Refuse the offer of food and drink

A. True
B. False

6. An Advanced Decision can enable a person to . . .

Refuse specific medical treatment

A. True
B. False

7. An Advanced Decision can enable a person to . . .

Refuse basic nursing care

A. True
B. False

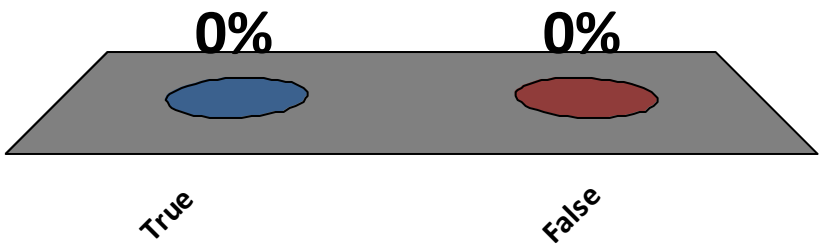
8. An Advanced Decision can enable a person to . . .

Refuse measures for maintaining comfort

A. True
B. False

9. An advance decision to refuse treatment has to be witnessed and signed.

A. True
B. False



7. Which of the following is **not** required to make an advanced decision to refuse life-sustaining treatment valid?

A: It is written, signed and witnessed.

B: It includes the statement ‘even if life is at risk’.

C: The treatments refused are clearly stated.

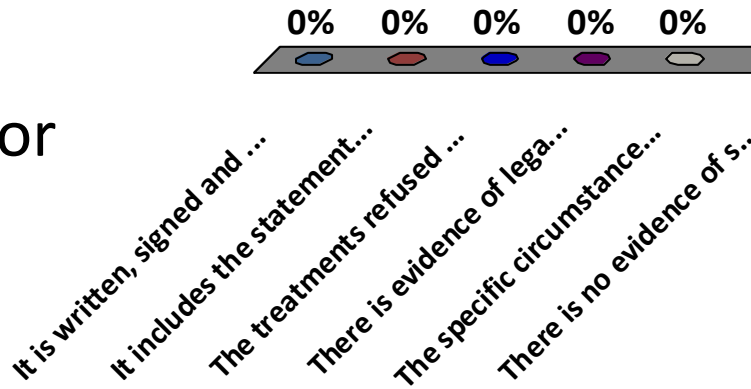
D: There is evidence of legal and medical advice given.

E: The specific circumstances of the refusal are described, and these are applicable.

F: There is no evidence of statements or actions to contradict the advance decision since it was made.

10. Which of the following is **not** required to make an advanced decision to refuse life-sustaining treatment valid?

A. It is written, signed and witnessed.
B. It includes the statement ‘even if life is at risk’.
C. The treatments refused are clearly stated.
D. There is evidence of legal and medical advice given.
E. The specific circumstances of the refusal are described, and these are applicable.
F. There is no evidence of statements or actions to contradict the advance decision since it was made.



- ACP and the Mental Capacity Act
- Lasting Power of Attorney

- For more on Advanced Care Planning visit

http://www.ncpc.org.uk/sites/default/files/AdvanceCarePlanning.pdf

DNACPR decisions

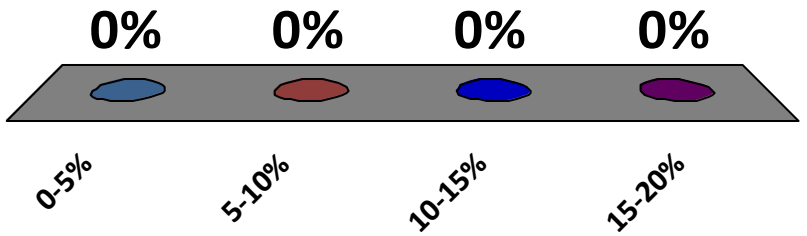
- Decide
- Discuss

- Document

How successful is CPR?

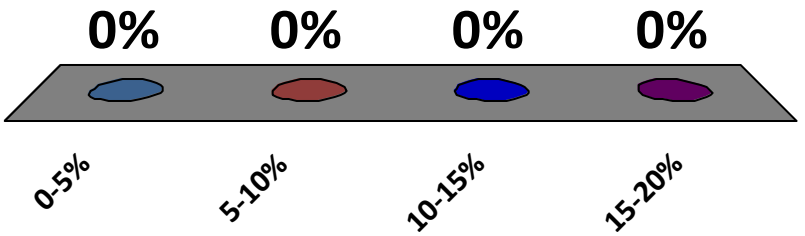
11. What is the percentage survival in an **out of hospital** arrest where CPR is attempted?

A. 0-5%
B. 5-10%
C. 10-15%
D. 15-20%



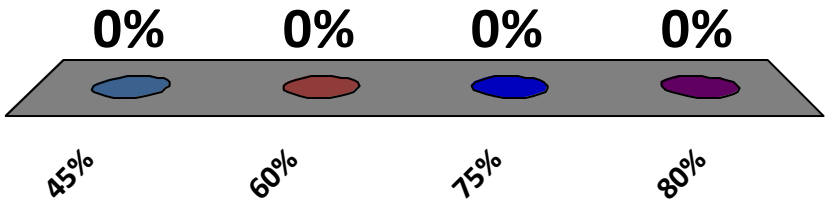
12. What is the percentage survival to discharge after CPR **in hospital**?

A. 0-5%
B. 5-10%
C. 10-15%
D. 15-20%



13. What is the percentage survival after CPR **in TV medical dramas**? (1996 study)

A. 45%
B. 60%
C. 75%
D. 80%



And in specific groups . . .

- Those with Karnofsky performance score ≤ 50?

(Requires considerable assistance with ADLs and frequent medical care)

- Those aged > 80yrs?

- Those with metastatic malignancy?

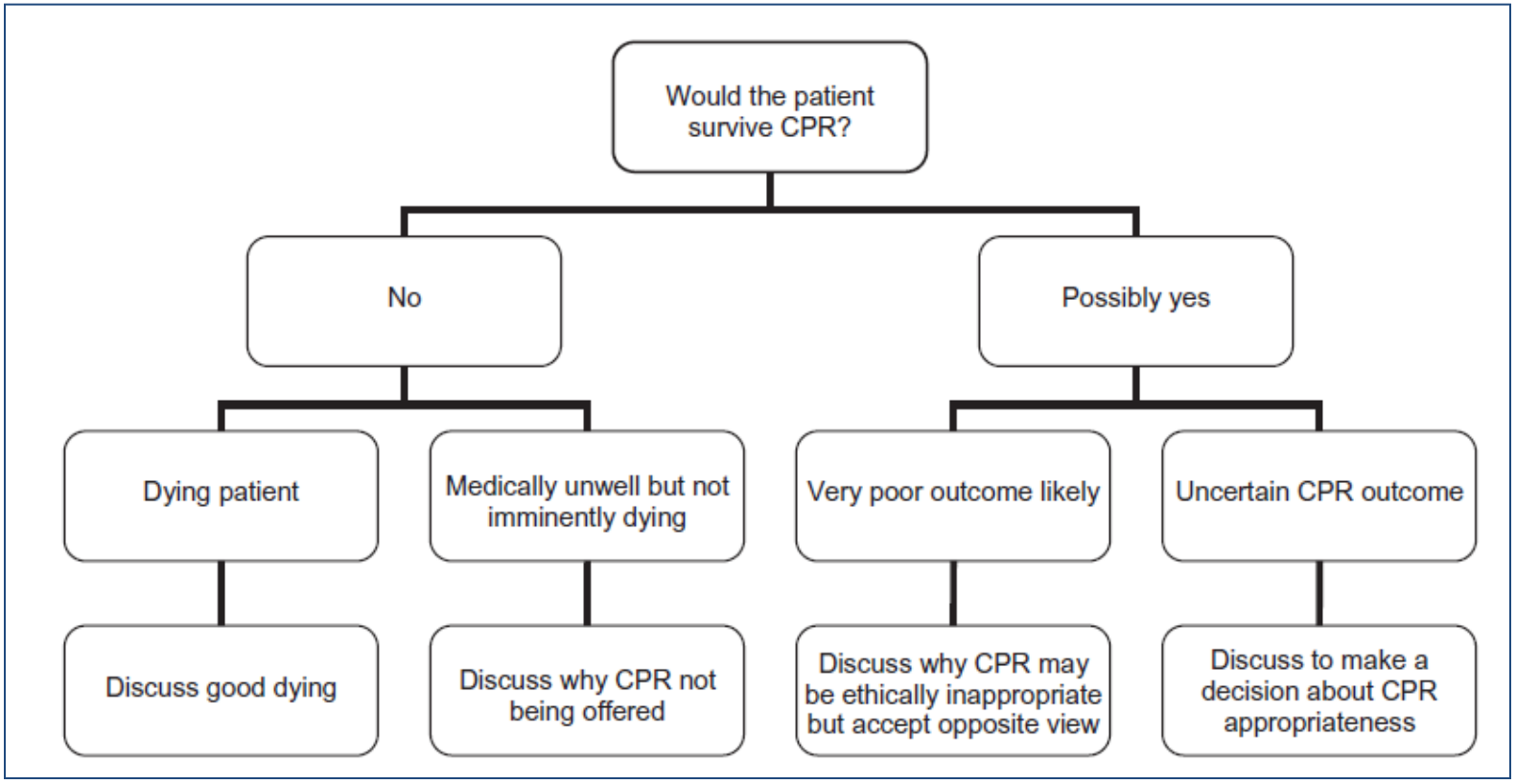
Survival to hospital discharge ≤3.5%

Those who do survive will do so less well and more dependant than they are now

96.5% will definitely NOT survive

Those with worst pre-arrest health status least likely to survive to discharge after CPR

CPR decision-making and discussion



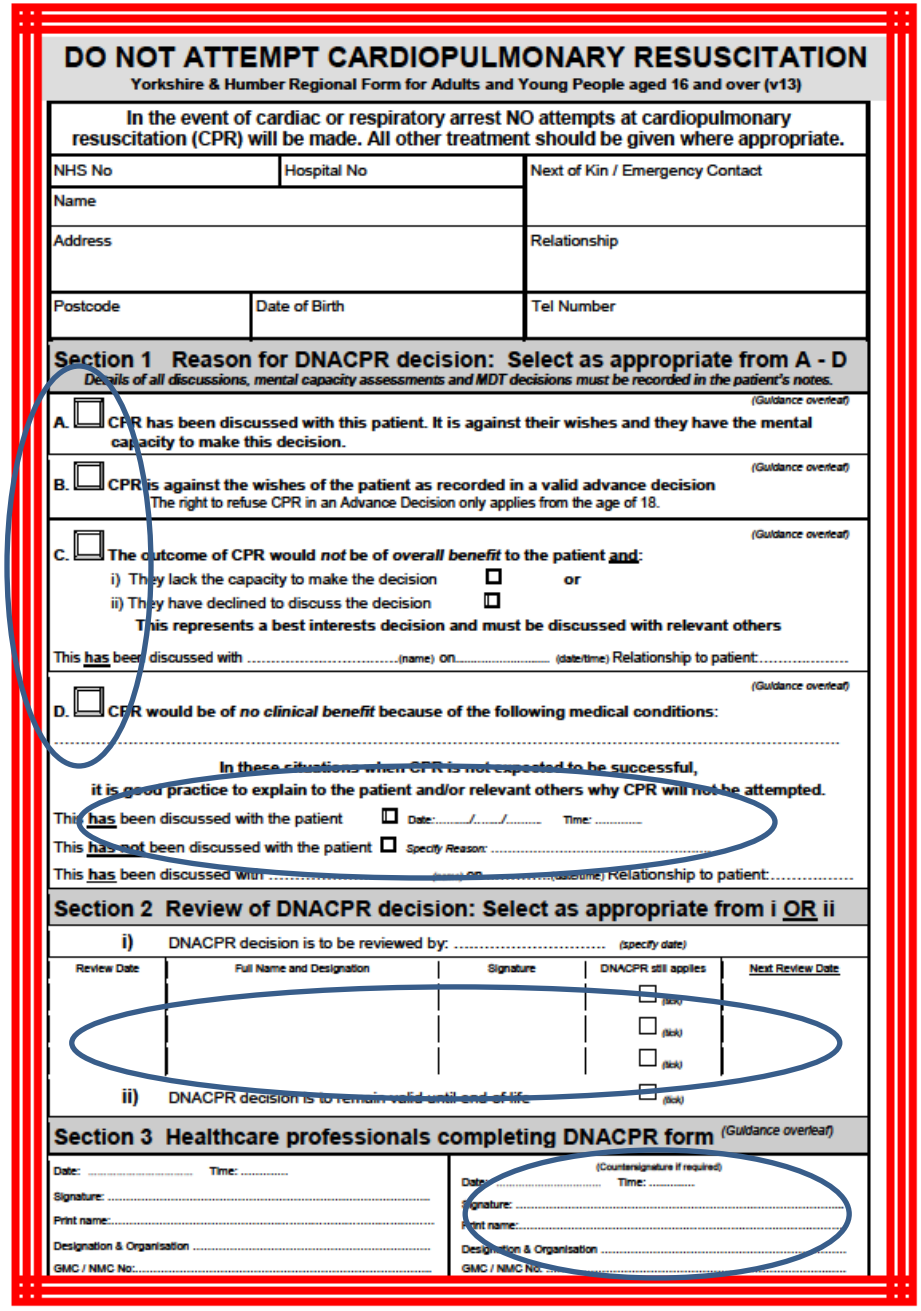
1 2 3 4

When a patient continues to demand CPR . . .

- Refer if needed
  - Specialist Palliative Care Team – medical review
  - Relevant specialist / MDT
- May be right to acquiesce in order to maintain trust. Views can change over time as condition changes.
- May be the right thing for that particular patient and family for them to die in an acute setting

Record in notes - discussion, or reasons why not discussed

Offer patients/family written information



DO NOT ATTEMPT CARDIOPULMONARY RESUSCITATION

Yorkshire & Humber Regional Form for Adults and Young People aged 16 and over (v13)

In the event of cardiac or respiratory arrest NO attempts at cardiopulmonary resuscitation (CPR) will be made. All other treatment should be given where appropriate.

NHS No	Hospital No	Next of Kin / Emergency Contact
Name		
Address		Relationship
Postcode	Date of Birth	Tel Number

Section 1 Reason for DNACPR decision: Select as appropriate from A - D

Details of all discussions, mental capacity assessments and MDT decisions must be recorded in the patient's notes.

(Guidance overleaf)

A. ☐ **CPR has been discussed with this patient. It is against their wishes and they have the mental capacity to make this decision.**

(Guidance overleaf)

B. ☐ **CPR is against the wishes of the patient as recorded in a valid advance decision**
The right to refuse CPR in an Advance Decision only applies from the age of 18.

(Guidance overleaf)

C. ☐ **The outcome of CPR would *not* be of *overall benefit* to the patient and:**
i) They lack the capacity to make the decision ☐ **or**
ii) They have declined to discuss the decision ☐
This represents a best interests decision and must be discussed with relevant others

This has been discussed with .....(name) on.....(date/time) Relationship to patient:.....

(Guidance overleaf)

D. ☐ **CPR would be of *no clinical benefit* because of the following medical conditions:**

.....

In these situations when CPR is not expected to be successful, it is good practice to explain to the patient and/or relevant others why CPR will not be attempted.

This has been discussed with the patient ☐ Date: ...../...../..... Time: .....

This has not been discussed with the patient ☐ *Specify Reason:* .....

This has been discussed with ..... (name) OR .....(date/time) Relationship to patient:.....

Section 2 Review of DNACPR decision: Select as appropriate from i OR ii

i) DNACPR decision is to be reviewed by: ..... *(specify date)*

Review Date	Full Name and Designation	Signature	DNACPR still applies	Next Review Date
			☐ (tick)	
			☐ (tick)	
			☐ (tick)	

ii) DNACPR decision is to remain valid until end of life ☐ (tick)

Section 3 Healthcare professionals completing DNACPR form (Guidance overleaf)

Date: ..... Time: .....
Signature: .....
Print name: .....
Designation & Organisation .....
GMC / NMC No: .....

(Countersignature if required)
Date: ..... Time: .....
Signature: .....
Print name: .....
Designation & Organisation .....
GMC / NMC No: .....

Other useful links

Barnsley BEST	**http://best.barnsleyccg.nhs.uk/**
Barnsley end of life care for patients and carer	http://barnsleyendoflifecare.co.uk/
Macmillan	https://www.macmillan.org.uk/
Barnsley Hospice	http://www.barnsleyhospice.org/home.aspx
Palliative care Formulary	http://best.barnsleyccg.nhs.uk/clinical-support/medicines/prescribing-guidelines/Palliative%20Care%20Formulary.pdf