



# Compassionate communities au Royaume-Uni

Prof Mark Taubert FRCP FRCGP

Consultant Palliative Medicine & Lead of Advance & Future Care Planning Strategy Group, NHS Wales Collaborative



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# Palliative Medicine for Health Care Professionals (MSc)

Duration: 3 years

Mode: Part time blended learning

Start date

✓ 01 September 2025



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# COMPASSIONATE CYMRU (FORMERLY 'BYW NAWR')

- Established in 2018
- Group established to link up patients, carers, community leaders, health and social care professionals and Welsh GOvernment
- Patients, carers, clinicians, charities (incl elderly care, disabilities), Welsh Government representatives, etc
- Meet every 2-3 months, more often during Covid-19
- Create national resources, events and initiatives, linked to government activities



## Grief is a public health issue

[Mary Ellen Macdonald](#) <sup>1</sup>, 

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PMCID: PMC11151893 PMID: [38727997](#)

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Grief is having a moment in Canada.

One impetus for this moment is the work of the Canadian Grief Alliance (CGA), formed by a group of concerned citizens who mobilized at the beginning of the COVID-19 pandemic in anticipation of an ‘avalanche of grief’ that would follow early on its heels. CGA inspired public conversations about grief and successfully lobbied to get grief onto the 2023 federal budget for the first time in Canadian history.

Grief is having a broader global moment, too. Growing from a 2018 international gathering of grief scholars who went on to publish the first academic paper advancing the concept of “Grief Literacy” (Breen et al., [2022](#)), a ground-swell of attention, activities, and developments has advanced thinking about grief as a public health issue. A recent conference in Halifax, Nova Scotia (September 2023), titled *Grief Literacy: From Theory to Action*, shone a light on international examples of grief literacy from around the world.



- **Network Mapping:**

- It involves identifying and mapping the diverse community assets that can provide support, such as hospices, schools, care homes, local businesses, community groups, and citizen-led initiatives.

- **Citizen-Led:**

- Emphasizes the role of citizens, volunteers and community members in building a more supportive environment.

- **Civic Charter:**

- The Compassionate City Charter provides a framework for developing a local public health approach to palliative and end-of-life care.

- **Community Engagement:**

- It encourages communities to join up top-down policy support with bottom-up community engagement and development.

- **Beyond Statutory Services:**

- Acknowledges the limitations of traditional health and social care services and highlights the importance of non-clinical community support.





Compassionate Cymru works with individuals, organisations and communities to improve how people in Wales care, die and grieve.

### About Us

- Compassionate Cymru's Journey ☐
- Mission Vision and Values ☐
- Members and Steering Group ☐

### Information & Support

- Planning for the future ☐
- Caring for a dying person ☐
- After someone has died ☐

### Get Involved

- Help build Compassionate Cymru in your area
- Examples of Compassionate Communities in action



## A COMPASSIONATE COUNTRY – A CHARTER FOR WALES

This Charter represents a commitment by our country to embrace a view of health and wellbeing that embraces citizenship and community empathy, directly supporting its citizens to address the negative health impacts of social inequality and marginalisation attributable to dying, death, bereavement and loss. Our Compassionate Country will by use of networks and influences, by dint of collaboration and co-operation, in partnership with social media and other means develop and support the following social changes to our Country's key institutions and activities.

Our Country will:

- **Recognise** that Wales is a community of communities, rich in its diversity and will seek to develop strategies through partnership to identify and address a range of end of life care, ageing, loss and bereavement needs.
- **Provide** information and support resources for the public and professionals that builds on: self-management and well-being initiatives; schemes to tackle loneliness and isolation and developments in social prescribing already underway.
- **Publicise** in print, social media, face to face and on line, our health and social care and local government policies, services, funding opportunities, partnerships, and public events that address 'our compassionate concerns' with living, with ageing, life-threatening and life-limiting illness, loss, bereavement, and long term caring.
- **Support** our hospices and care homes to implement community development programmes involving local citizens in end of life care, loss and bereavement.
- **Encourage** our schools, colleges and universities to have policies or guidance documents in place for dying, death, loss, bereavement and care.
- **Support** our workplaces and trade unions to have policies or guidance documents in place for dying, death, loss, bereavement and care.
- **Work** with our places of worship to have dedicated groups to support those with: end of life care needs; are affected by loss or bereavement; are lonely and/or isolated and long term carers.
- **Support** our prisons and homeless organisations to plan for end of life care and loss and bereavement.
- **Work** with our museums and art galleries to include experiences of ageing, dying, death, loss or care as part of their exhibition programmes.








## Features

# Advance and future care planning: strategic approaches in Wales

 Mark Taubert<sup>1, 2</sup> and Lauren Bounds<sup>3</sup>

Correspondence to Professor Mark Taubert, Palliative Medicine, Velindre NHS Trust, Cardiff CF14 2TL, Caerdydd, UK;  
mtaubert@doctors.org.uk



## Abstract

**Background** In Wales, the term advance care planning now falls under the wider umbrella term 'Future Care Planning', which also includes patients with diminished mental capacity and their significant others, to engage in deciding and planning future care. Over the last 5 years, work has been undertaken to create education formats, resources and national documents, and this has been informed by a national Advance and Future Care Planning steering group and national conference, which included patient and carer representatives. This helped collate relevant data.

**Aim** We outline key strategic approaches in Wales with regard to future care planning.

**Results** With data from our national conference and through feedback from stakeholders, a national repository of distinct resources, forms and education formats has been created. The approach seeks to cater for the disparate need of the Welsh population; there is not merely one format for multiple scenarios, but a choice of approaches, communication strategies and documents to suit bespoke needs.


**Conclusion** Advance and future care planning is an approach with many different facets. In Wales, we have found that some patients prefer a clearly set out, legally binding 'Advance Decision to Refuse Treatment' to guide their care, while others prefer a softer, guiding approach captured through an Advance Statement. All these formats are available to patients, carers and healthcare professionals, together with explanatory guidance notes, through a central Welsh website. Next steps involve getting a central electronic repository for these forms, which is accessible to healthcare providers and to patients.

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## Features

# Advance and future care planning: strategic approaches in Wales

 Mark Taubert<sup>1, 2</sup> and Lauren Bounds<sup>3</sup>

Correspondence to Professor Mark Taubert, Palliative Medicine, Velindre NHS Trust, Cardiff CF14 2TL, Caerdydd, UK;  
mtaubert@doctors.org.uk



conditions.<sup>6</sup> An agreement was reached by the Welsh End of Life Care Board and national advance care planning representatives, to introduce the term *future care planning* as an umbrella term to capture both ACP, as well as *best interest decisions* for individuals who *lack* decisional capacity at the outset. The term 'future care planning' had been suggested by a patient representative who felt it described its premise more clearly than the more ambiguous term 'advance'. It was further noted that frequently, the word 'advance' was mistyped or misunderstood as 'advanced'. This definition involving the word 'future' was endorsed by Welsh Government and operationalised into national work streams.<sup>7-9</sup> See [box 1](#) for definitions.

# 2025

collaborative.nhs.wales/implementation-groups/end-of-life-care/



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## End of Life Care Implementation Board

The End of Life Care Implementation Board provides national leadership and support and acts as a forum to drive forward change and oversee health boards' efforts to deliver the Welsh Government's vision for improving end of life care in Wales.

Our aim is for people in Wales to have a healthy, realistic approach to dying, and to be able to plan appropriately for the event.

We want them to be able to end their days in the location of their choice – be that home, hospital or hospice and we want them to have access to high quality care wherever they live and die, whatever their underlying disease or disability.

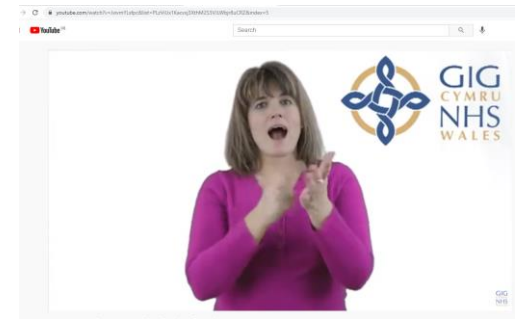
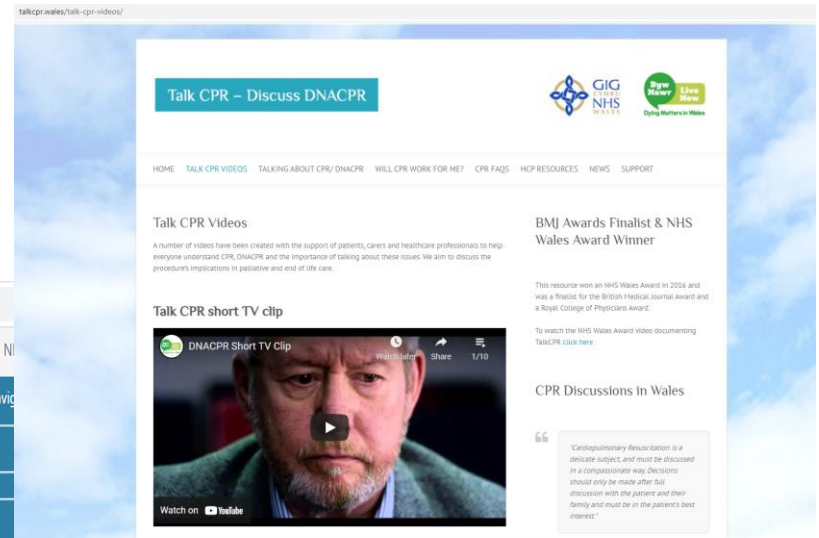
## DNACPR

'Sharing and Involving - a clinical policy for Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) for adults in Wales', a summary of the key changes in version 4 (2020), and information for patients.

## Advance and Future Care Plans

Information, forms and guidance for patients, carers and healthcare professionals relating to Advance and Future Care Planning.

**@ProfMarkTaubert** <https://compassionate.cymru/www.wales.nhs.uk/AFCP>





# THIS STARTED A BIG INFO AND EDUCATION CAMPAIGN LINKED TO COMPASSIONATE WALES:

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website of the year

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Healthcare  
Network

## This is not Casualty - in real life CPR is brutal and usually fails

Only 3% of over-80s survive CPR and 1.9% of secondary cancer patients. It's time we doctors stopped meddling and let such patients die with dignity



87k 52

Mark Taubert

Wednesday 3 February  
2016 09.49 GMT



CPR can be a life-saver – but a palliative care patient is unlikely to survive it. Photograph: Alamy

Most popular

Adding vitamin D to food reduces deaths, say scientists



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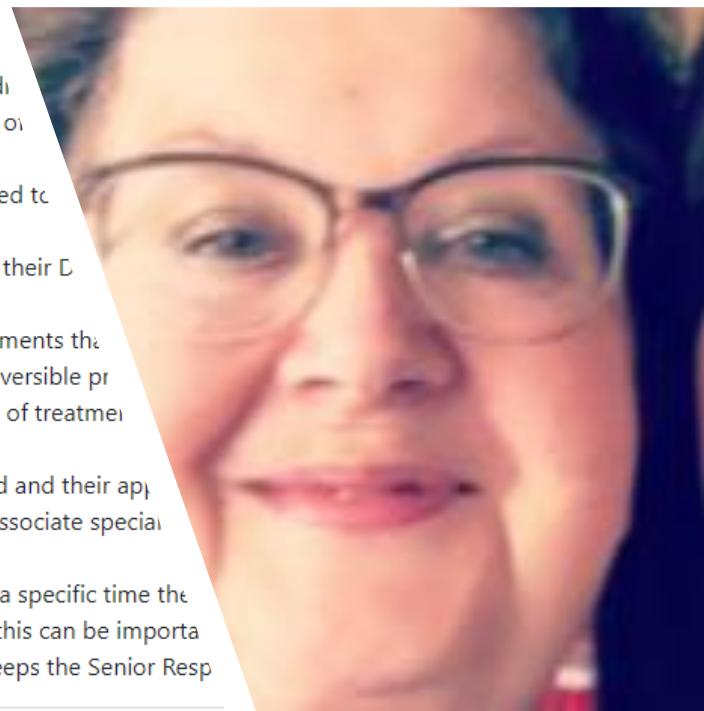
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## Key changes and clarifications

- Expansion on the concept of 'Natural Anticipated and Accepted Death' (NAA)
- DNACPR/CPR discussions with patients should be offered, especially if it is felt
- Reiteration that blanket approaches to DNACPR are never acceptable and each
- Decisions regarding CPR are a major healthcare decision and should be given a
- Clarification on who can hold discussions and who can sign section 5 of the DNACPR form - AHPs like paramedics
- Everyone who is involved in DNACPR decisions and forms should have read the All Wales version of the policy
- Rather than tasking patients and their loved ones with a decision on whether they want CPR, healthcare professionals should explain the professional (and team) why a DNACPR decision is necessary, and how low the success of CPR is, as outlined by the Royal College of Physicians' 'Talking about Dying Report 2018' [↗](#)
- A reminder of other existing forms relating to Advance and Future Care Planning, including the DNACPR form, which are filled in by patients to specify their refusals and location of All Wales versions on the NHS website
- There is now a simpler URL to house the policy: [www.wales.nhs.uk/DNACPR](http://www.wales.nhs.uk/DNACPR)
- To clarify that patients, contrary to occasional media reports on this issue, are never asked to sign a DNACPR form
- Once a decision has been reached, to offer each individual and/or their proxy a copy of their DNACPR form to visiting healthcare professionals in future
- The policy reiterates that a DNACPR form does not preclude people from all other treatments that they may want to receive ongoing chemotherapy or other treatments that may help reverse potentially reversible problems
- Legal updates including distress versus harm when assessing risks of discussing ceilings of treatment
- Concept of 'shared understanding' in the context of CPR and DNACPR
- Cross-border forms including ReSPECT from England, and DNACPR forms from Scotland and their application
- Need for Senior Responsible Clinician, usually a GP or circumstances a senior nurse or associate specialist to sign section 6
- Clarification that when a senior responsible clinician cannot personally sign the form at a specific time then a proxy can sign where they agree with a DNACPR decision, this can be noted in section 6 of the form - this can be important if the patient is in a care home or setting where individuals are isolating or quarantining, but still keeps the Senior Responsible Clinician on the form



# Cancer campaigner Keith Cass who sold own funeral tickets dies

🕒 19 April 2019



WALES NEWS SERVICE

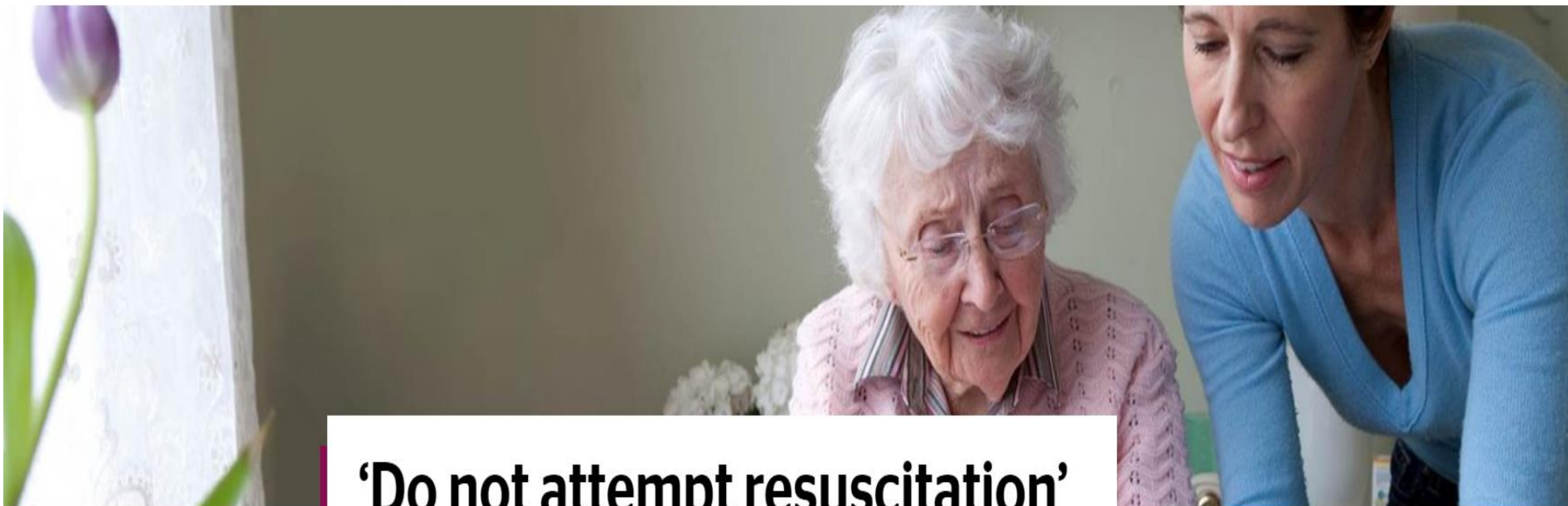
| Keith Cass said his funeral would include a comedian, a band and dancing

**A cancer campaigner who sold tickets to his own funeral in order to raise more money for charity has died.**

Keith Cass, 72, from Cardiff, who was diagnosed with prostate cancer in 2006, organised his "best and most different funeral" to raise £500,000.



## Later Life Care

[Home care](#)[Carers & caring](#)[Financing care](#)[Housing options](#)[End of life](#)[Care services directory](#)[End of life](#) > [Planning for the end of life](#) >

## ‘Do not attempt resuscitation’ decisions (DNACPR)

*Thinking about whether you would want to be resuscitated in the event of an emergency is a complex issue. We tackle the confusion around DNACPR decisions, and explain how they are made.*

 6 MIN READPRINT  
PAGE

In this article

## Views And Reviews

## Yes, doctors need to talk about dying, but what if patients start the conversation?

BMJ 2018 ; 363 doi: <https://doi.org/10.1136/bmj.k4648> (Published 05 November 2018)

Cite this as: BMJ 2018;363:k4648

Article

Related content

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Responses

Mark Taubert, consultant in palliative medicine, honorary senior lecturer, strategic lead for advance care planning<sup>1 2</sup>

Author affiliations ▾

[mtaubert@doctors.org.uk](mailto:mtaubert@doctors.org.uk)

Follow Mark on Twitter [@DrMarkTaubert](#)

A recent report called on doctors to initiate conversations about dying earlier on in a patient's illness trajectory. **Mark Taubert** describes how patients are key to improving this

I was talking to Neil, an IT worker in his 50s with advanced cancer, about his wishes for when things got worse over the coming year. What would he want medics to try if he was unable to communicate; were there any interventions he'd want to forgo? Neil and I had never met before and already we were talking about the big taboo topic: our dying moments and death.

A recent report by the Royal College of Physicians highlighted how doctors struggle with talking about dying, making them reluctant to broach the subject with patients. It concluded that many people are so focused on the benefits of modern medicine that talking about the inevitable—dying—seems like an unpleasant distraction, a waste of time.

Doctors and nurses can be willing colluders in patients' and their families' narrative ("Let's fight this and beat cancer"). Some patients may even feel that talking about death and dying implies that a doctor knows something they don't.

I've often been mildly apologetic when I start talking about advance care planning and what lies ahead, but I'd way in: "I'm sorry to bring something up that may seem a bit alien—

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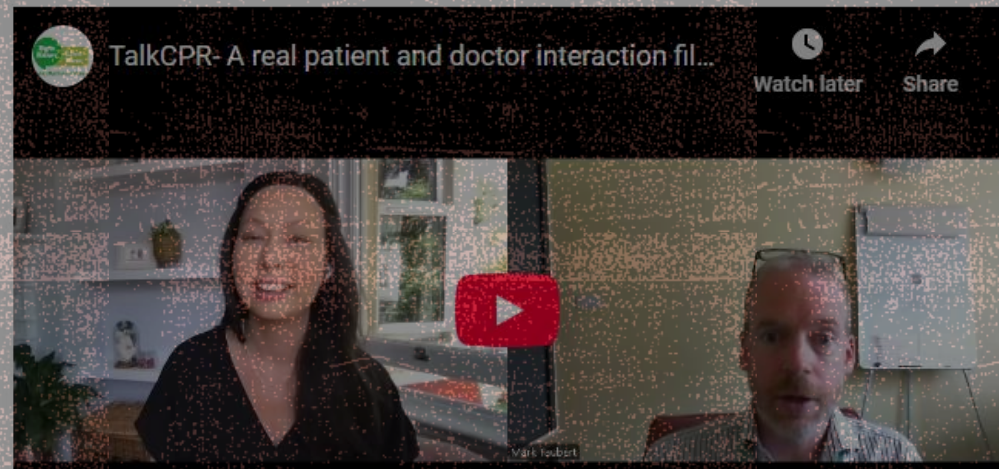
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We can make  
things clear





# DESIGNING PATIENTS INTO EVERYTHING





# Top Tips

## CPR & DNACPR DISCUSSIONS



DNACPR Top Tips on how to start conversations for healthcare providers

20,655 views • 15 Feb 2016

👍 83

💬 1

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...

# TREATMENT 'LADDER' APPROACH



DNACPR Top Tips on how to start conversations for healthcare providers

20,655 views • 15 Feb 2016



83



1



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Byw Nawr - Live Now

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# QR CODE FOR PATIENT/NOK TALKCPR VIDEOS ON YOUTUBE



# CONVERSATION APPROACHES INCL “WHAT MATTERS MOST TO YOU?”

- Work at UK level with What Matters Most Charter and at regional level with Compassionate Cymru.
- Goal of finding out what sort of person they are and what level of intervention they think is acceptable
- **“What matters most to you, especially towards the end of life?”**
- What goals do they have. Any opinions on treatments they wouldn't want?
- **“It may seem strange for me to bring this up now that you are feeling better, but what do you want us to do differently next time you get admitted?”**

How about appointing an Lasting Power of Attorney for Health and Welfare, and/or writing an Advance Decision to Refuse Treatment (ADRT)?





# What matters conversations

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## WHAT MATTERS MOST CHARTER

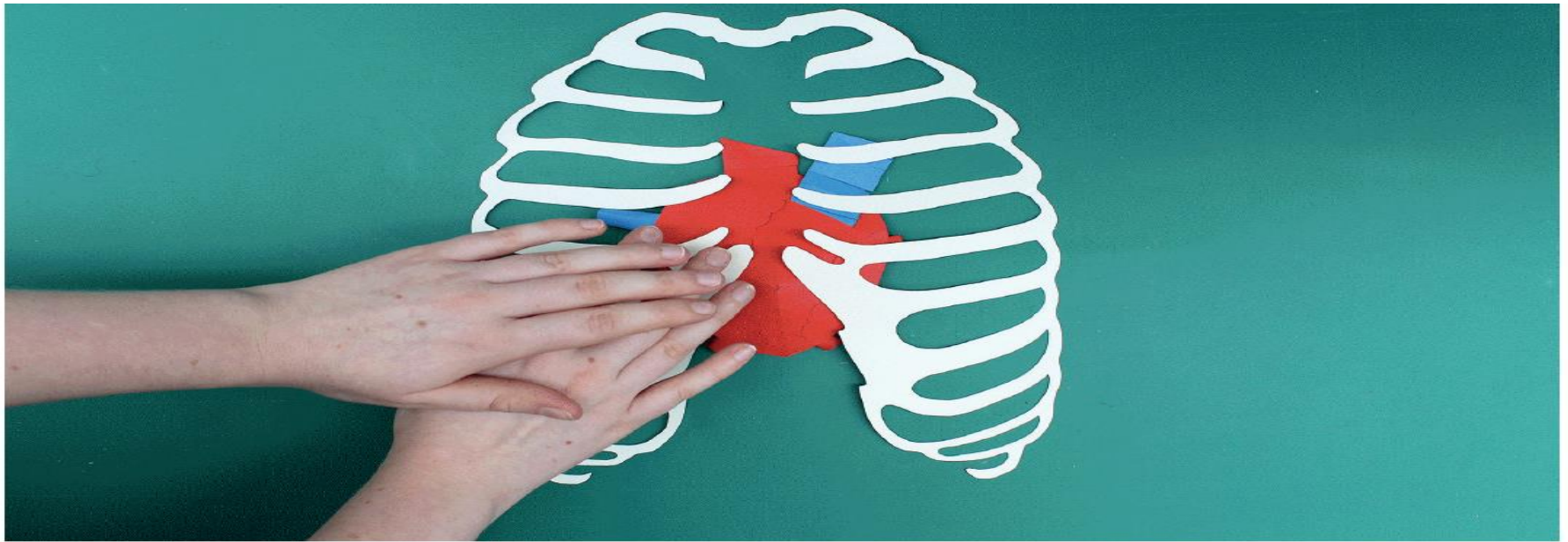
### **A personal & compassionate community approach to care and treatment planning**



Recent experience during the COVID-19 pandemic has highlighted problems with advance care planning (ACP) conversations. Often such conversations don't take place, or when they do, they are hurried and medically focussed. Rather than being life-affirming and positive they tend to concentrate on place of death and what treatment you are prepared to receive. The many organisation involved in this project believe that a series of normal conversations with families, friends and occasionally professionals regarding your interests and wishes for the future would help us all. That way, bringing end of life issues to the table will seem less scary and more natural.

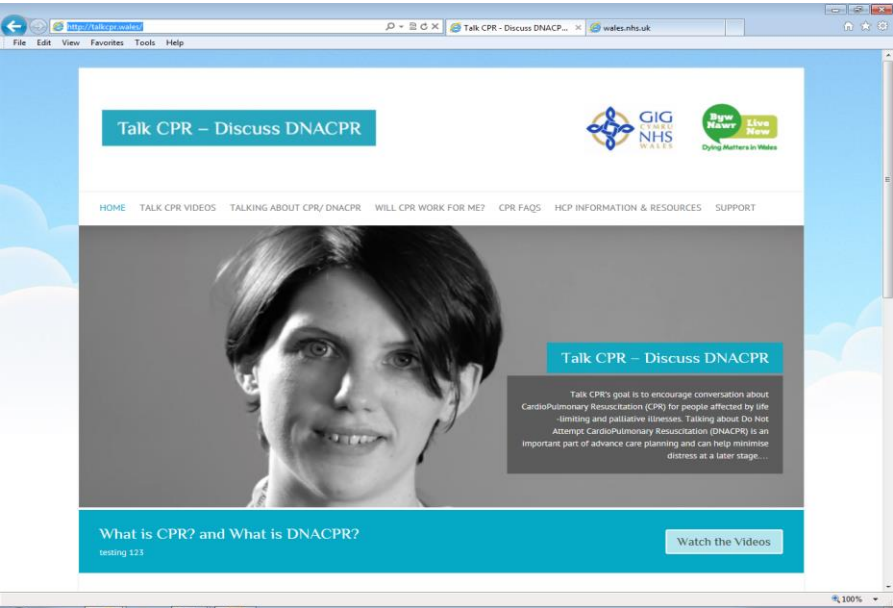
To help clarify the group's aims, we have developed a 'Charter'. It is not long or complicated. We encourage you to read, reflect, and get your organisation to adopt the Charter. We would love to hear from you. After all, talking about important things in life and what 'what matters to you' can surely never be wrong?







# 'Conversation starters':



<http://talkcpr.wales>

#TalkCPR



<http://advancecareplan.org.uk>



# CULTURAL DIFFERENCES AND APPROACHES

→ ↺ aljazeera.com/opinions/2021/4/30/how-to-discuss-do-not-resuscitate-decisions-with-patients



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US Secretary of State Blinken calls on Gaza groups to end rocket attacks



**OPINION**

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## 'Do not resuscitate' discussions: Can we do better?

*COVID-19 must not be used as an excuse to avoid difficult discussions about Do Not Attempt CPR decisions.*



**Mark Taubert**

Palliative Medicine Consultant in the UK's National Health Service



30 Apr 2021



harm. Others may have cultural or even religious reasons for not wishing to engage or very reasonably wishing to obtain further information. Some of my Muslim patients have queried whether it is acceptable. And it is: according to Saudi Arabia's Presidency of the Administration of Islamic Religion and Ifta, as stated in their Fatwa no. 12086, DNACPR forms are an acceptable part of practice.

## Advance & Future Care Planning in Wales – initial consensus data from conference participants

Posted on [December 27, 2019](#)

Nikki Pease, Consultant in Palliative Medicine, Cardiff, Wales

Mark Taubert, National Strategic Lead for Advance/Future Care Planning, NHS Wales



*"Shared Decision making should also include an ability to share the decisions that have been agreed on"*

### Background:

In 2019, BMJ Supportive & Palliative Care featured a write-up of the proceedings of a [national conference on Future Care Planning in Wales](#). 'Future Care Planning' (FCP) was introduced within NHS Wales as an umbrella term to encompass both Advance Care Planning (which, by definition [1] involves patients who have decisional capacity at the time of formulating an anticipatory plan), and Best Interests Decision making, for individuals who lack 'decisional capacity' and therefore cannot make informed choices regarding health and social care needs.

Since then, conference organisers have been collating, analysing and evaluating the copious data from this national conference, to establish how it can best inform, the future care planning priorities for Wales, prudent healthcare and the value based healthcare approach. In parallel, through collaboration with The Marie Curie Palliative Care Research Centre, Cardiff University, a more detailed evaluation is under way to provide research-grounded framework analysis, which in turn will recommend documents for practical use in day-to-day future care planning. Current findings have identified the need for a FCP document with a simple logo for ease of recognition, communication and transferability. This final document is planned for later in 2020. A briefer summary evaluation can be found [here](#), to outline how comments and agreed key points from participants have been categorised into themes.





### CATEGORIES

Select Category



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[SPIDER as a framework to formulate eligibility criteria in qualitative systematic reviews](#)  
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#### SYSTEMATIC REVIEW

[Distress Thermometer in breast cancer: systematic review and meta-analysis](#)  
11 May 2021

#### SYSTEMATIC REVIEW

[Implantable cardioverter defibrillator devices: when, how and who should discuss deactivation with patients: a systematic literature review](#)  
7 May 2021

#### CASE REPORT

[Dantrolene for muscle rigidity in progressive supranuclear palsy](#)  
5 May 2021

#### SYSTEMATIC REVIEW

[Informal caregivers and advance care planning: systematic review with qualitative meta-synthesis](#)  
5 May 2021

### BMJ CAREERS

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Consultant in Palliative Medicine

# AFCP RESOURCES VIA WWW.WALES.NHS.UK/AFCP

collaborative.nhs.wales/implementation-groups/end-of-life-care/advance-and-future-care-plans/



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## Advance and Future Care Plans

\*\*\* Please scroll down to access Advance and Future Care Planning Forms, COVID-19 Treatment Escalation Plan and for Covid-19 updates \*\*\*

### Introduction

This page includes information and links for Advance and Future Care Planning.

For definitions and information videos go to [our Advance Care Plan information website](#).

These resources and forms are for patients and healthcare professionals, with the aim of providing a One Wales sharing and involving approach.

The documents have been peer reviewed by the Advance and Future Care Planning Strategy Group (AFCP) for Wales, which sits under the auspices of the NHS Wales End of Life Care Board and the Deputy Chief Medical Officer for Wales.

The decision making to inform these forms involved extensive patient and carer engagement.

The AFCP Group has patient representation and is pan-Wales. It has also been informed by [data collated](#) during a [National Future Care Planning Conference](#) in Wales.



Name:	<input type="text"/>	NHS no:	<input type="text"/>
Address:	<input type="text"/>	Date of birth:	<input type="text"/>
Postcode:	<input type="text"/>	Hospital no:	<input type="text"/>
GP and practice:	<input type="text"/>		

**This form is to record the advance care wishes of a person with mental capacity. The decisions recorded here are not legally binding, but should inform any clinical decisions made on behalf of the person.**

Date:

## 1 INVOLVING OTHERS IN DECISION MAKING

Have you appointed a **Lasting Power of Attorney**?

Name(s): <input type="text"/>	Tel no(s): <input type="text"/>
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If not, is there **someone you would like to be consulted** if the doctors ever have to make treatment decisions on your behalf?

Name(s): <input type="text"/>	Tel no(s): <input type="text"/>
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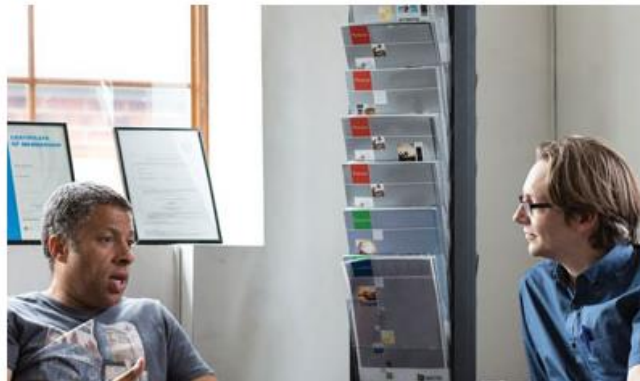
## 2 DEPENDENTS

Do you have anyone **dependent** on you for their care (e.g. children, partner or elderly relatives)?  
Record who, what relationship, and age:

If so, have you made any plans for their care if you are unable to look after them?  
Record brief details:



## Our Work



**LOCAL COMPASSIONATE INITIATIVES  
INCLUDING SOCIAL PRESCRIBING**

Health & Wellbeing

Projects that support health and wellbeing

extending community shops, advice, cafe, training, and much more

more

[Click here](#)



## *Mission Vision and Values*



### *Mission*

We are a national movement belonging to and given life by families, individuals, communities and organisations throughout Wales. We aim to help people access and offer information, care and support in a compassionate way within their communities. Our particular focus is on care and support at the end of people's lives, whenever that happens.

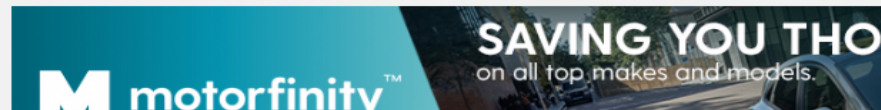
### *Vision*

Our vision is to be a considerate and caring nation that comes together to develop compassionate approaches to support people's health and wellbeing. Whether you are living with ill health or dementia, or are experiencing loneliness and isolation, or dealing with grief, loss and bereavement, Compassionate Cymru is there for you.

We want everyone in Wales to enjoy the benefits of belonging, to receive help at a time when they need it most and to give help when they are able.







## Compassionate Country Wales

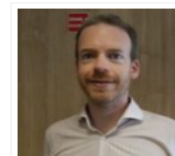
Posted on July 17, 2018



*In this blog, Mark Taubert talks to Julian Abel about Compassionate Communities and what a Compassionate Country Wales may look like.*



*Dr Julian Abel,  
Consultant in  
Palliative care and  
Director of  
Compassionate  
Communities UK*



*Dr Mark Taubert,  
Clinical Director for  
Palliative Medicine at  
Velindre NHS Trust  
& Associate Editor for  
BMJ SPcare*

**MT:** Bore da, Julian, croeso y Gymru. Great to chat to you. Let's get straight to the bare bones. Vaughan Gething, Cabinet Secretary for Health in Wales, announced on July 3rd that Wales is to become a *Compassionate Country*. You and I are here to chat about what this may look like, on the background of the [Compassionate Communities and Compassionate Cities](#) approach and all the work that has been done [worldwide and in the UK](#).

**JA:** Diolch Mark, yes, so first of all, what did Vaughan Gething say in his speech in Tredegar in Wales? In his speech, he quoted from the [Compassionate City Charter](#) (1). This is a document that is a short synthesis of the civic public health approach to palliative and end of life care. In our article, [Palliative Care – The New Essentials](#) (2), we describe how palliative care can be viewed as the interplay of four cogs:

- Specialist palliative care,
- Generalist palliative care,
- Compassionate communities and the
- Civic approach encapsulated in the compassionate city charter.



ENDLESS  
HOPE  
HOPELESS  
END

