Fy Mywyd,
Fy Nymuniadau

My Life,
My Wishes

My Life My Wishes

Advance Care Planning in Parkinson's

Jane Price
Parkinson's Nurse Advanced Practitioner

Session objectives

- Consider what advanced care planning (ACP) means in the context of Parkinson's disease.
- Increase awareness of the importance of starting conversations around ACP for people living with Parkinson's disease.
- Identify the real and perceived barriers that impact on when and how these conversations take place.
- Identify how the clinician can introduce and promote ongoing ACP conversations

“Advance Care Planning is a voluntary process of discussion between an individual and their care providers irrespective of discipline”

“It is to make clear a person’s wishes in anticipation of a deterioration in the individual’s condition in the future, with attendant loss of capacity to make decisions and/or ability to communicate wishes to others”

National End of Life Care Programme. (2007)

"Advance Care Planning is a process that supports adults at any age or stage of health in understanding and sharing their personal values, life goals, and preferences regarding future medical care"

International Consensus Definition of Advance Care Planning (Sudore, et al. 2017)

Neurology®

May 28, 2019; 92 (22) ARTICLE

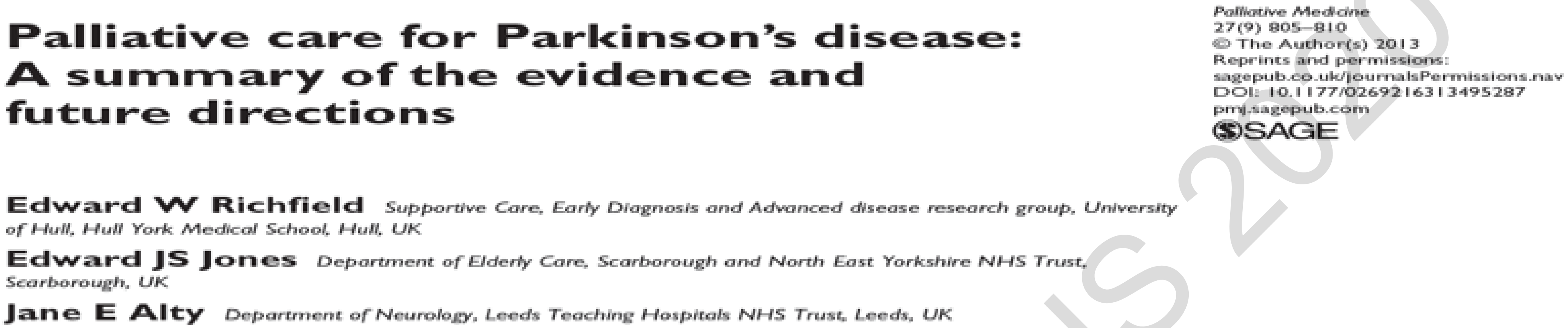
Framing advance care planning in Parkinson disease

Patient and care partner perspectives

Hillary D. Lum, Sarah R. Jordan, Adreanne Brungardt, Roman Ayele, Maya Katz, Janis M. Miyasaki, Anne Hall, Jacqueline Jones, Benzi Kluger

First published April 26, 2019, DOI: https://doi.org/10.1212/WNL.0000000000007552

- Currently no best practice standards on how to incorporate ACP into PD care
- ACP may be influenced by patient and partner perceptions and misperceptions
- Motor and non motor symptoms in PD influence decision making
- Optimal engagement with patients and carers needed to facilitate a patient and care partner framework



Palliative care for Parkinson's disease: A summary of the evidence and future directions

Palliative Medicine
27(9) 805–810

DOI: 10.1177/0269216313495287
pmj.sagepub.com
SAGE

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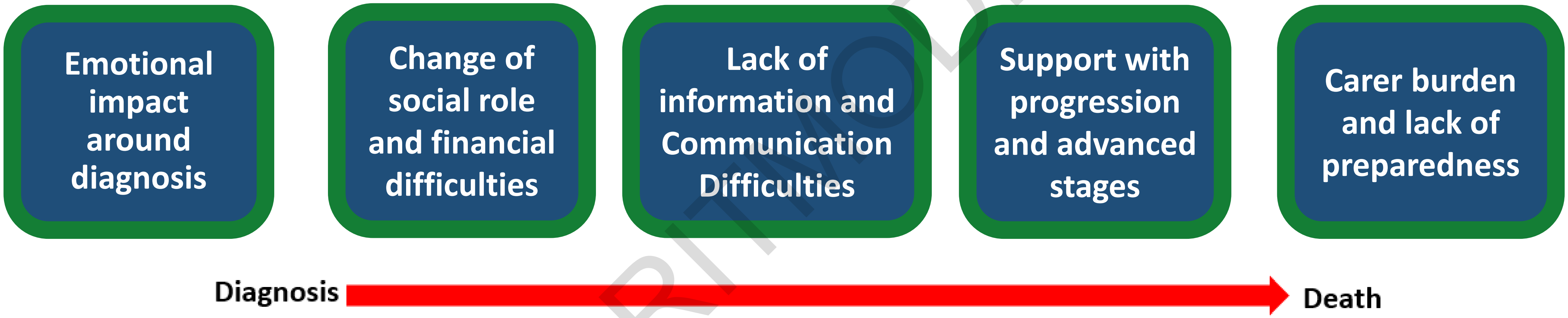


Emotional impact around diagnosis

Change of social role and financial difficulties

Lack of information and Communication Difficulties

Support with progression and advanced stages

Carer burden and lack of preparedness

Diagnosis → **Death**

- Limited evidence for timing of palliative interventions
- "Information Tension"
- Need for sustainable integrated palliative services for PD

We research so many things throughout our life

Triggers to completing an ACP

- A new diagnosis of a life changing condition.
- A change/ progression in an existing disorder.
- New treatment options or change in treatment aims to consider.
- A need to consider a different care setting.
- The death of a significant other.
- A change in personal circumstances.
- Changes within the family dynamics.

End-of-life care conversations with heart failure patients:
a systematic literature review and narrative synthesis

Stephen Barclay, Natalie Momen, Steve Case-Upton, Isla Kuhn and Elizabeth Smith

Most patients expect the clinician will raise the subject

SO

Most patients wait for the clinician to start the conversation

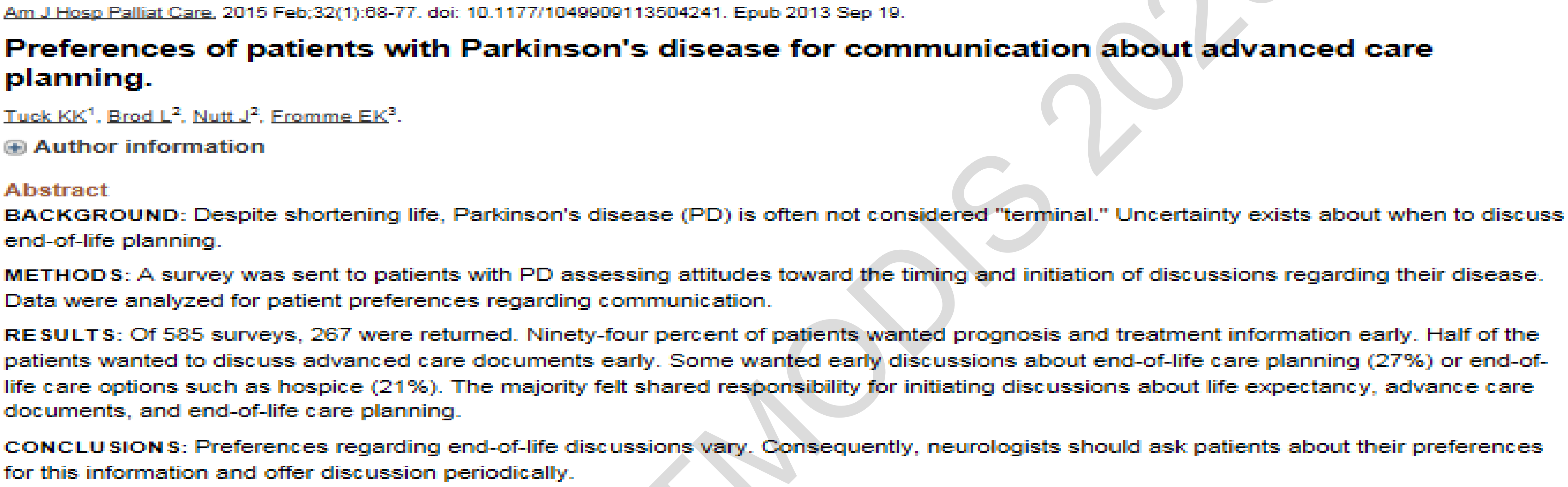
BUT

Most clinicians wait for cues from the patient

SO

Risk that the conversation doesn't take place

Barclay et al (2011)



Am J Hosp Palliat Care. 2015 Feb;32(1):68-77. doi: 10.1177/1049909113504241. Epub 2013 Sep 19.

Preferences of patients with Parkinson's disease for communication about advanced care planning.

Tuck KK[1], Brod L[2], Nutt J[2], Fromme EK[3].

⊕ Author information

Abstract

BACKGROUND: Despite shortening life, Parkinson's disease (PD) is often not considered "terminal." Uncertainty exists about when to discuss end-of-life planning.

METHODS: A survey was sent to patients with PD assessing attitudes toward the timing and initiation of discussions regarding their disease. Data were analyzed for patient preferences regarding communication.

RESULTS: Of 585 surveys, 267 were returned. Ninety-four percent of patients wanted prognosis and treatment information early. Half of the patients wanted to discuss advanced care documents early. Some wanted early discussions about end-of-life care planning (27%) or end-of-life care options such as hospice (21%). The majority felt shared responsibility for initiating discussions about life expectancy, advance care documents, and end-of-life care planning.

CONCLUSIONS: Preferences regarding end-of-life discussions vary. Consequently, neurologists should ask patients about their preferences for this information and offer discussion periodically.

- 75% of participants felt they themselves should broach the topic of ACP
- 94% wanted information on prognosis and treatment early on
- 50% wanted communication about documentation for ACP

Front Neurol. 2019 Jan 14;9:1157. doi: 10.3389/fneur.2018.01157. eCollection 2018.

The Role of Palliative Care in Chronic Progressive Neurological Diseases-A Survey Amongst Neurologists in the Netherlands.

Walter HAW[1], Seeber AA[1], Willems DL[2], de Visser M[1].

- Challenge of when is the right time to discuss ACP
- Fewer than 10% of neurologists surveyed initiate ACP discussion at time of diagnosis
- Reasons for delay included concern about causing a perception of abandonment, causing distress or threatening any sense of hope
- Almost half delayed conversation until onset of significant physical or cognitive decline

Barriers to ACP…..

Documentation

Legal Aspects

Environment

Time Constraints

Confidence

Cause distress and strong emotions

Maintaining Hope

Lack of Training

Support

Busy

Practicalities

Consistency

Culture

npj | Parkinson's Disease

www.nature.com/npjparkd

PERSPECTIVE OPEN

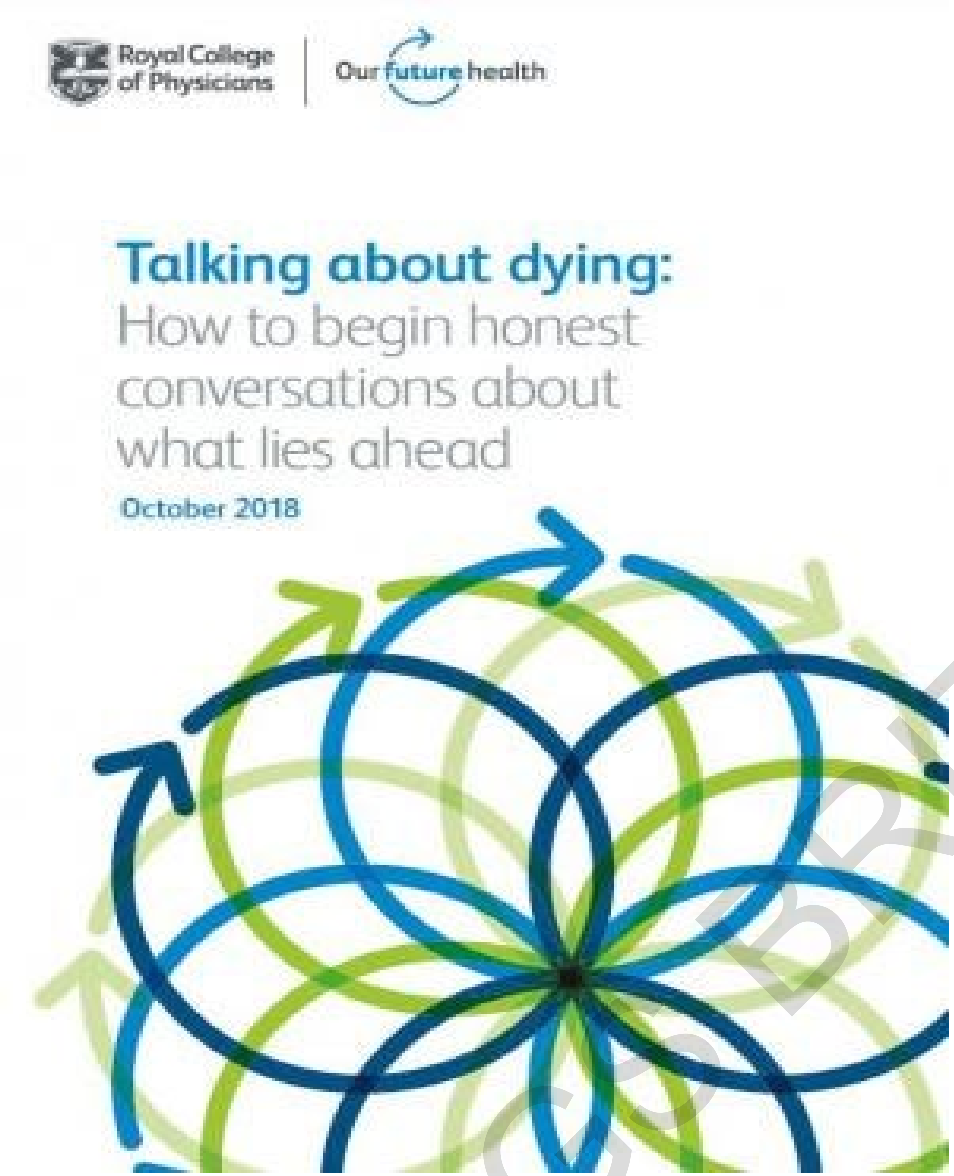
Advance care planning in Parkinson's disease: ethical challenges and future directions

Leonard L. Sokol[1,2,3*], Michael J. Young[4], Jack Paparian[5], Benzi M. Kluger[6], Hillary D. Lum[7], Jessica Besbris[8], Neha M. Kramer[9], Anthony E. Lang[10], Alberto J. Espay[11], Ornella M. Dubaz[1,12], Janis M. Miyasaki[13], Daniel D. Matlock[7], Tanya Simuni[1] and Moran Cerf[14,15]

Recent discoveries support the principle that palliative care may improve the quality of life of patients with Parkinson's disease and those who care for them. Advance care planning, a component of palliative care, provides a vehicle through which patients, families, and clinicians can collaborate to identify values, goals, and preferences early, as well as throughout the disease trajectory, to facilitate care concordant with patient wishes. While research on this topic is abundant in other life-limiting disorders, particularly in oncology, there is a paucity of data in Parkinson's disease and related neurological disorders. We review and critically evaluate current practices on advance care planning through the analyses of three bioethical challenges pertinent to Parkinson's disease and propose recommendations for each.

npj Parkinson's Disease (2019)5:24 ; https://doi.org/10.1038/s41531-019-0098-0

- PD is progressive and associated with dementia in up to 80% pts in advanced stages
- One study showed that a substantial subset of patients with PD with mean disease duration of 9.8years and MoCA 24.5 (n=≥26) showed impaired decisional capacity in domains of understanding, appreciating and reasoning (Abu Snineh *et al* 2017)


Royal College of Physicians | Our future health

Talking about dying:
How to begin honest conversations about what lies ahead

October 2018

Key Recommendations

- Asking patients if they would like to have the conversation and how much information they would want.
- Initiate shared decision making including advance care planning in line with patient preferences
- A process not a tick box and can and should be initiated at any point.
- Be aware of language used and involve all relevant

- How have you been coping recently?
- Do you think about/ plan for the future?
- Thinking of the future, what do you hope for?
- What worries you the most?
- Have you given any thought to what kinds of treatment you would or wouldn't want?
- Have you made your wishes known?

Closing the conversation

- Summarise to check mutual understanding
- Involvement of significant others, such as family, carers, community team, general practitioner or specialists.
- Leave with a plan- what is the agreement to continue or review at later date

Making it everyone's business

My Life, My Wishes

Advance Care Planning

My Life, My Wishes is the Advance Care Plan from Powys Teaching Health Board.

Advance Care Planning can give you and your loved ones control over your future wishes.

GIG CYMRU NHS WALES
Bwrdd Iechyd Addysgu Powys
Powys Teaching Health Board

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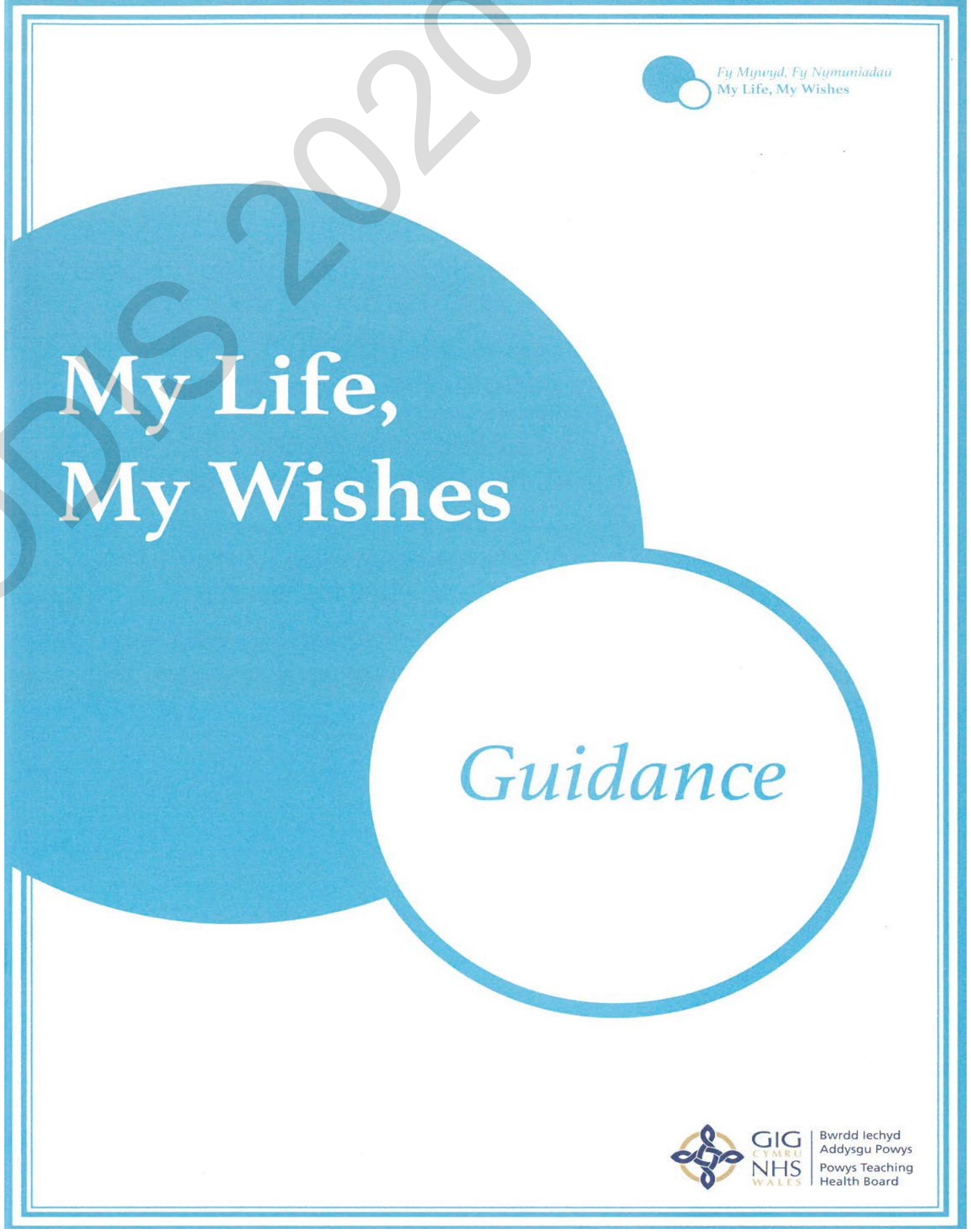

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Guidance

GIG CYMRU NHS WALES
Bwrdd Iechyd Addysgu Powys
Powys Teaching Health Board

Key features of document

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My Life,
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- Person held
- Accessible and plain language
- ACP for everyone - do not need to be unwell to complete!
- Available in both Welsh and English
- Prompts to explore and discuss other ACP measures
  e.g. LPOA, DNACPR, Making a will, ADRT
- Not legally binding and can be altered
- Can be empowering

Section 1

Fy Mywyd,
Fy Nymuniadau

My Life,
My Wishes

People Important to Me:

Name:	**Relationship:**	**Contact number:**	**Other info (e.g. emergency contact, next of kin, main carer, attorney.)**

Health and Social Care Professionals Involved in my Care:

Name:	**Role:**	**Contact number:**

Section 2 - Thinking Ahead

My Values and Beliefs – These are the things that are most important to me

(for example, my view on life, my religious/spiritual beliefs, my preferred language and the name I like to be called)

My Health - What has been happening to me

(for example, details of any illnesses and treatments, and my understanding of the future)

Section 3 - My Future

Specific Wishes - My wishes and priorities for my future care

(For example, where and how I would like to be cared for)

Specific Wishes - What I do NOT want to happen to me

(for example, what I worry about or fear happening to me)

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Section 4 - My Last Days

What is most important to me in the last days of my life

(For example, who I would want with me when I am nearing the end of my life, any religious or spiritual practices that I would like, music that I would like to hear)

Where I would prefer to be cared for at the end of my life:

First Preference: ....

....

Second Preference: ....

....

- Thoughts regarding CPR
- LPA for Health and Welfare and/or Legal and Financial matters
- After my Death
- Will
- Organ donation
- Wishes regarding burial/ cremation
- Funeral wishes, plans or policies held

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Section 5 - After my death

What to do with my Internet accounts

(For example, who I would like to manage my social media accounts and on line bank accounts)

....

....

....

Details of my responsibilities, and the arrangements that I have made for them (For example, dependant family members or pets):

....

....

Additional Information

Please use this space for updates, changes to your plan or anything you wish to add.
Please sign and date changes or additions on page 11

My Other Documents:

(You can keep your other documents in your folder, otherwise please state location)

Document	(if available, please tick box)	Date and location
DNACPR (Do not attempt cardio-pulmonary resuscitation)	☐	....
Lasting Power of Attorney	☐	....
Advance Decision to Refuse Treatment	☐	....
'This is me'/Hospital Passport (used in hospitals and care homes)	☐	....
Any other documents:	☐	....
....	☐	....
....	☐	....

If you would like help to complete any of these documents or to discuss them further, please ask your Health Care Professional.

Please sign and date on completion:

Signed: .... Date: ....

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I never thought about internet passwords before, now my family would now where my book is

I feel it's a weight lifted knowing its there in black and white, I wouldn't want them all arguing

We've been able to talk about brain donation, they know its what I want

I liked the way my husband also got one, it made me feel less targeted

I was worried what would happen if I lost my memory

I have been able to put things in here that if I spoke to my daughter about she would say it was bad luck

I picked up extra copies and have given them out to friends

Its made it so much easier for me to bring the subject up with my family

Blog | **BMJ Supportive & Palliative Care**

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

Posted on December 27, 2019 by BMJSPCblog

Nikki Pease, Consultant in Palliative Medicine, Cardiff, Wales

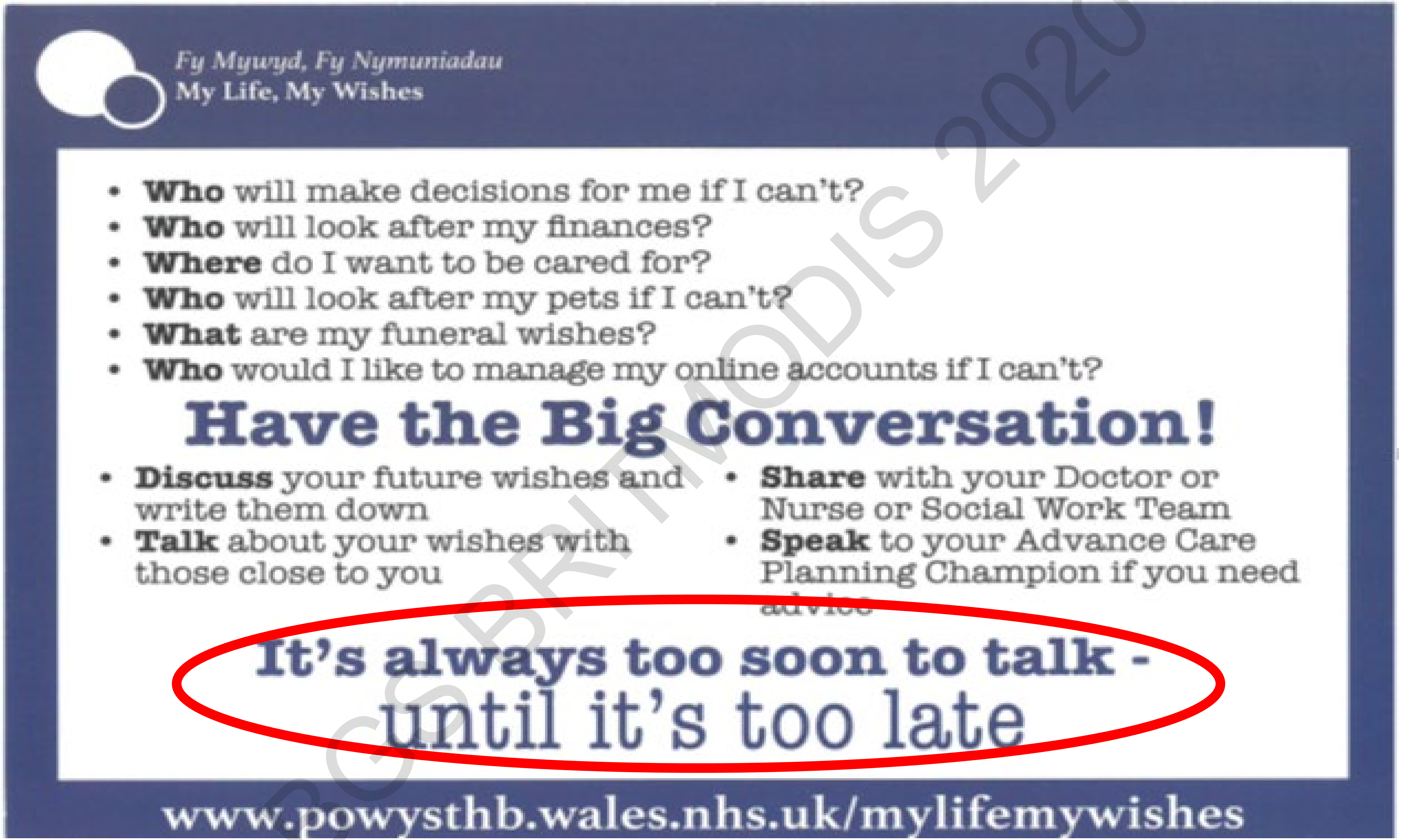
Mark Taubert, National Strategic Lead for Advance/Future Care Planning, NHS Wales

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

- Education for public and professionals
- Review of how data is stored and shared
- Challenges in sharing established wishes
- Concerns about paper copies and call for a central electronic repository
- Shared electronic patient records that enable direct input from patients

So, why have an ACP?...

Supporting conversations ahead of a crisis, before individuals and/or families are overtaken by circumstances and events they didn’t expect or have the opportunity to consider.



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- **Who** will make decisions for me if I can't?
- **Who** will look after my finances?
- **Where** do I want to be cared for?
- **Who** will look after my pets if I can't?
- **What** are my funeral wishes?
- **Who** would I like to manage my online accounts if I can't?

Have the Big Conversation!

- **Discuss** your future wishes and write them down
- **Talk** about your wishes with those close to you
- **Share** with your Doctor or Nurse or Social Work Team
- **Speak** to your Advance Care Planning Champion if you need advice

It's always too soon to talk -
until it's too late

www.powysthb.wales.nhs.uk/mylifemywishes

THANK YOU

If we wait until we're ready, we'll be waiting for the rest of our lives.

Lemony Snicket

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