

3 primary Carer needs THROUGHOUT the whole of the dementia journey

- Continuous Education (enough at each stage for the present and near future stages)
- Building Confidence (for the stages ahead)
- ALWAYS available Support, when THEY need it 24/7

TOPICS for Carer education might include

- Should YOU "care" or place your PWD in a care-home and/or Nursing home /or Hospice and WHEN? Who makes the decision and how do they make that decision?
- How to "care" – what normal caring looks like and what best practice looks like
- Finding and engaging in activities that benefit the PWD
- Administration – important stuff like LPAs
- Who to go to when SPECIFIC "difficult things" happen
- Research initiatives (by dementia type)
- How to develop skills that you might need – like Smart-phone, Laptop, Social Media etc
- PWD Support organisations, split by each stage of each dementia
- Carer support organisations e.g. TIDE and Age-UK

Using a common language

A list of on-line resources that are helpful to Carers of PWDs. The language used is invariably based on the FAST Scale and terminology.

The 3-stage dementia terminology is not precise enough and causes too much waffle and confusion.

Examples of videos on YouTube:

British Video: <https://www.youtube.com/watch?v=KHUijkp-kj0> understanding sensory changes in Dementia

British Video: <https://www.youtube.com/watch?v=R0C2ug7AbTY> Fundamental needs in dementia

Careblazers: <https://www.youtube.com/watch?v=Cy6RsmQf0G0> normal thinking vs Dementia thinking

British Columbia: Outline of dementia and it's stages: https://www.youtube.com/watch?v=9CIKwGA-ILw&ab_channel=AlzheimerBC

WellMed is a US charitable foundation and has comprehensive educational videos: https://www.youtube.com/watch?v=tansVVDM0fE&t=14s&ab_channel=WellMedCharitableFoundation and one useful video about death https://www.youtube.com/watch?v=qvyVrktLMog&ab_channel=WellMedCharitableFoundation

Dementia Australia: <https://www.youtube.com/@DementiaAustralia> is the Aussie go-to organisation for Carers <https://www.dementia.org.au/>

Dealing with Continence issues is one of the main triggers for Family placing their PWD in a Care-Home. Giving Care-Givers the knowledge and tools to deal with this topic possibly will have the greatest impact of keeping PWDs where they most want to be – in their home. Here is one example – there are a few, https://www.youtube.com/watch?v=elx9LG4qN30&ab_channel=ContinenceFoundationofAustralia

Here is a best practice example, (which is the first of 6) https://www.youtube.com/watch?v=-zOxo7MplE&t=3s&ab_channel=ContinenceFoundationofAustralia

Two videos about Continence and helping carers maintain the dignity of PWDs including “timed-toileting” https://www.youtube.com/watch?v=wFhHhgXUrY&ab_channel=DementiaCareHub

A good “how to” early after diagnosis: commonly used versus better idea! https://www.youtube.com/watch?v=CWnlLUjkgXg&ab_channel=DementiaCareblazers

And another https://www.youtube.com/watch?v=sbJvguaVp6Q&ab_channel=DementiaCareblazers (in this one, it is said that Incontinence is the #1 reason that Carers place PWDs in CareHomes.)

<https://www.letsbambu.com/> An organisation (USA based) that aims to support all Carers of PWDs. As well as a website, they have a great YouTube channel and here’s an example of their description of stages 6 and 7 (late-stage Dementia) https://www.youtube.com/watch?v=1x_1NjAs2Q0&ab_channel=BambuCare

Answers about Alzheimers is a great educational channel, perhaps useful to Carers at the diagnosis stage? https://www.youtube.com/watch?v=pSykJy08naQ&ab_channel=AnswersAboutAlzheimer%27s there are separate videos for each stage.

Another US organisation: James L West centre: https://www.youtube.com/watch?v=boD6E9YYX2E&ab_channel=JamesL.WestCen

[terforDementiaCare](#) This "Center" has several YouTube videos including ones on toileting and bathing.

Dementia Careblazers is an organisation that sets out "how to" deal with aspects of Care Giving and shows examples of common practice vs best practice ideas. https://www.youtube.com/watch?v=ymp2SgFhNtw&ab_channel=DementiaCareblazers There are many videos from this organisation. One that helped me understand and deal with "aggression" is https://www.youtube.com/watch?v=SEp4-TN5pmA&ab_channel=DementiaCareblazers

This video is part of a series called "Sharing the Journey", a resource for dementia caregivers that is supported by the (Canadian) Victoria Hospitals Foundation and produced by Island Health. https://www.youtube.com/watch?v=mUe8yCVJoUs&t=6s&ab_channel=IslandHealth

For more information visit www.islandhealth.ca/dementia-videos

IOWA Geriatric Education Center has an excellent video covering "End of life" issues. This is a little "Doctor to Doctor" level https://www.youtube.com/watch?v=uPZZ2PBylo&ab_channel=IowaGeriatricEducationCenter

UCLA (American university) <https://www.uclahealth.org/medical-services/geriatrics/dementia/caregiver-education/caregiver-training-videos> is a website with a directory of their videos, which is a useful approach. It can be "searched", for example if a PWD suddenly starts having hallucinations and/or delusions, with or without aggressive behaviours, it does help a Carer to be able to search using those terms.

https://www.youtube.com/watch?v=a1RvE8fP0yo&t=2795s&ab_channel=KeilaHaynes is a very useful video insofar as it describes many aspects of end-of-life that one would like to ask about yet common courtesy might prevent most people from asking....easier to see on a YouTube video at home!

If using a PC, you will be used to YouTube offering you additional choices of related videos and also used to the fact that, if you know the "terms" others use in their titles and tags, it's relatively easy to search YouTube. However, there are noticeably more YouTube videos that are unhelpful or irrelevant than useful.....so CareGivers will need time.