



This document is a quick guide about palliative care identification tools for use with people living with dementia. It has been designed by the Focus on Dementia team for staff supporting people living with dementia. It is hoped this document will make it easier to choose a tool to use or find out more about the choice of tools available.

## Background and related work

There are a number of tools available to help identify people who could benefit from a palliative care approach at an earlier stage. The ihub Community Care team produced the *Palliative care identification tools comparator*<sup>1</sup> which lists some of these tools for a range of medical conditions or population groups.

Identifying when someone living with dementia needs palliative care can be difficult<sup>2</sup>.

The [Scottish Intercollegiate Guideline Network \(SIGN\)](#) are currently working on a dementia guideline for Scotland, it is due to be published in Spring 2023. The SIGN guideline may contain more information on palliative care tools for people living with dementia. In the meantime, the Focus on Dementia team are keen to provide this quick guide of some of these tools to help people supporting people living with dementia use them at the appropriate time.

## Tools

We have included four tools that may be useful to help identify people who could benefit from a palliative care approach at an earlier stage for people living with dementia: [FAST](#), [IPOS-Dem](#), [NECPAL](#), and [SPICT](#). The Focus on Dementia team does not endorse any specific tool over another – citations and the brief summary text is provided for information.

### FAST

Functional Assessment Staging (FAST) was designed for use with people living with Alzheimer’s disease. It is a seven stage scale that has been in use for a while, however, we have been unable to find a reliable source to provide a link to the tool itself.

### Further reading

Title	Publication type	Setting	Population	Summary
<a href="#">Functional Assessment Staging (FAST) in Alzheimer’s Disease: Reliability, Validity, and Ordinality</a> <sup>3</sup>	Study article	Various	People with dementia	It describes the background to FAST being developed and table one lists the FAST scale. It presents the results of three experiments about the “reliability, validity, and progressive ordinality of FAST” <sup>3</sup> . Participants for each experiment are reported – numbers are small. The authors report the “that FAST is a reliable and valid assessment technique for evaluating functional deterioration in AD patients throughout the entire course of the illness.” <sup>3</sup> It does not however give a threshold for palliative care

## IPOS-Dem

Integrated Palliative care Outcome Scale for Dementia (IPOS-Dem) is a relatively new tool. It is free to use and can be downloaded from the [IPOS website](#) (registration required). The tool is designed to be used by unqualified care staff with people living with dementia in care home settings.

### Further reading

Title	Publication type	Setting	Population	Summary
<a href="#">Development of a caregiver-reported measure to support systematic assessment of people with dementia in long-term care: the Integrated Palliative care Outcome Scale for Dementia</a> <sup>4</sup>	Study article	Residential care homes	Care givers	This study involved semi-structured interviews with care giving staff, health care professionals and family in 3 residential care homes for people with dementia in London. It reports on the development of the IPOS-Dem tool. The study found "IPOS-Dem is an acceptable caregiver-reported measure for people with dementia in long-term care settings to support comprehensive assessment by unqualified caregiver staff." <sup>4</sup> It also concludes that further evaluation is required.
<a href="#">How can a measure improve assessment and management of symptoms and concerns for people with dementia in care homes? A mixed-methods feasibility and process evaluation of IPOS-Dem</a> <sup>5</sup>	Study article	Residential care homes	People with dementia and care givers	This is a follow up study to Ellis-Smith <i>et al</i> 2017 <sup>4</sup> . It involved implementing IPOS-Dem in 3 residential care homes to better understand how it could be used. It was found that introducing IPOS-Dem to routine care was "feasible and acceptable" and that it "can support comprehensive and [sic] assessment and management of symptoms and concerns." <sup>5</sup> It also concludes that a trial of the effectiveness of IPOS-Dem should be carried out.

## NECPAL

Necesidades Paliativas (NECPAL) has been adapted from SPICT. The [tool](#) is free to download and it comes with information about how to use it. It is designed for use in health and social care settings with people who have advanced chronic conditions, including dementia.

### Further reading

Title	Publication type	Setting	Population	Summary
<a href="#">NECPAL tool prognostication in advanced chronic illness: a rapid review and expert consensus</a> <sup>6</sup>	Rapid review and expert consensus	Various	Variety of advanced chronic conditions	It used SPICT to develop a new tool – NECPAL – to identify palliative care needs for people with various advanced chronic conditions in a variety of settings.

## SPICT

The Supportive and Palliative Indicator Tool (SPICT) [website](#) has information about the development of the tool and it can also be downloaded for free. SPICT can be used with people who have advanced chronic conditions, including dementia. A lot has been written about SPICT and the website contains a list of these publications.

### Further reading

Title	Publication type	Setting	Population	Summary
<a href="#">Identifying palliative care needs in residential care</a> <sup>7</sup>	Study article	Residential aged care facilities (RACFs)	187 residents (mean age 82.4 years)	It used a "prospective case-finding approach towards end-of-life care planning by testing a combination of two commonly used methods for early identification of risk of dying." <sup>7</sup> This article found that the use of a surprise questions and SPICT "may assist in the early identification of palliative care needs for residents who are at risk of dying." <sup>7</sup>

## References

1. ihub. Palliative care identification tools comparator. 2018 [cited 2021 Nov 22]; Available from: <https://ihub.scot/media/2079/palliative-care-identification-tools-comparator.pdf>
2. National Institute for Health and Care Excellence. Dementia: Assessment, management and support for people living with dementia and their carers. 2018 [cited 2021 Nov 22]; Available from: <https://www.nice.org.uk/guidance/ng97/evidence/full-guideline-pdf-4852695709>
3. Sclan SG, Reisberg B. Functional Assessment Staging (FAST) in Alzheimer's Disease: Reliability, Validity, and Ordinality. *Int Psychogeriatr.* 1992;4(3):55-69
4. Ellis-Smith C, Evans CJ, Murtagh FEM, Henson LA, Firth AM, Higginson IJ, *et al.* Development of a caregiver-reported measure to support systematic assessment of people with dementia in long-term care: The Integrated Palliative care Outcome Scale for Dementia. *Palliat Med.* 2017;31(7):651-60
5. Ellis-Smith C, Higginson IJ, Daveson BA, Henson LA, Evans CJ, BuildCare. How can a measure improve assessment and management of symptoms and concerns for people with dementia in care homes? A mixed-methods feasibility and process evaluation of IPOS-Dem. *PloS one.* 2018;13(7):e0200240
6. Gómez-Batiste X, Turrillas P, Tebé C, Calsina-Berna A, Amblàs-Novellas J. NECPAL tool prognostication in advanced chronic illness: a rapid review and expert consensus. *BMJ Support Palliat Care.* 2020:bmjspcare-2019-002126
7. Liyanage T, Mitchell G, Senior H. Identifying palliative care needs in residential care. *Aust J Prim Health.* 2018;24(6):524-9