

# Supporting People with Learning Disabilities through the Palliative Care Journey

## NHS Greater Glasgow and Clyde Learning Disabilities and Palliative Care Pathway

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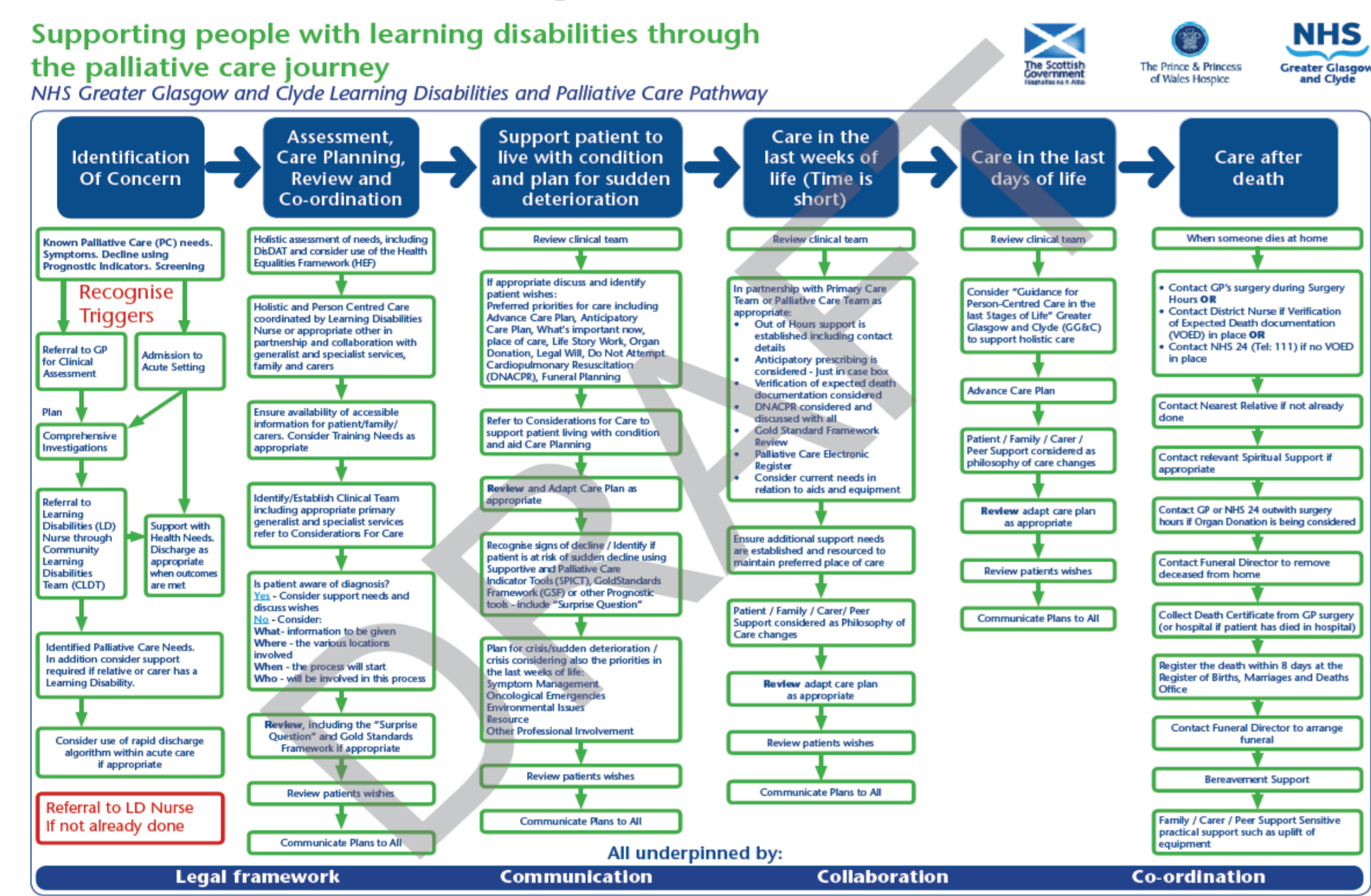


### Introduction

In response to the acknowledged complexities of caring for people with learning disabilities (PWLD) through the palliative care journey<sup>1</sup>, the development of a care pathway and supporting document “Considerations for Care” was facilitated through the work of the project “Learning Disabilities and Palliative Care : Building Bridges –Supporting Care”. This was further endorsed in Recommendation 26 of Keys to Life , the Scottish Government Learning Disability Strategy<sup>2</sup>. This project hosted by the Prince and Princess of Wales Hospice (PPWH) was jointly led by senior practitioners representing both Learning Disability Services (GG&C) and Palliative Care Services (PPWH).

### The Care Pathway

Supporting people with learning disabilities through the palliative care journey  
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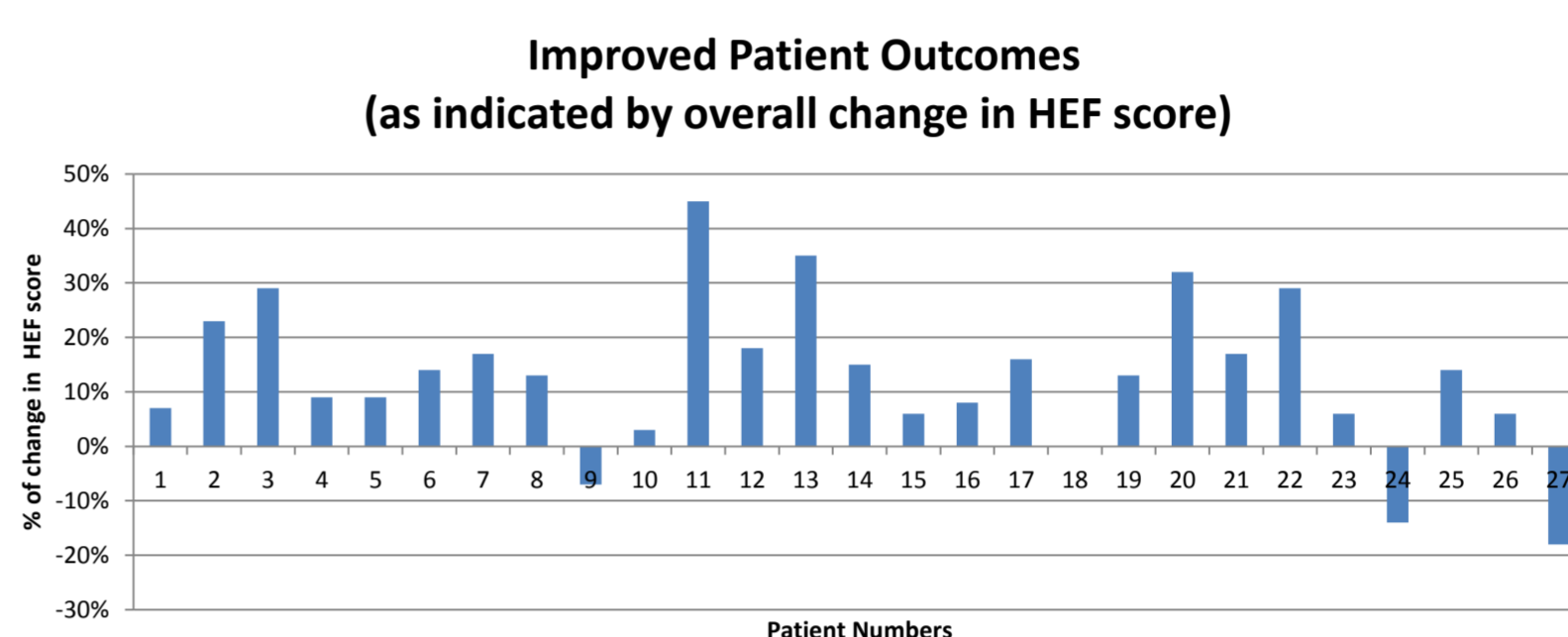


### Evaluation

The pathway was evaluated using the following tools

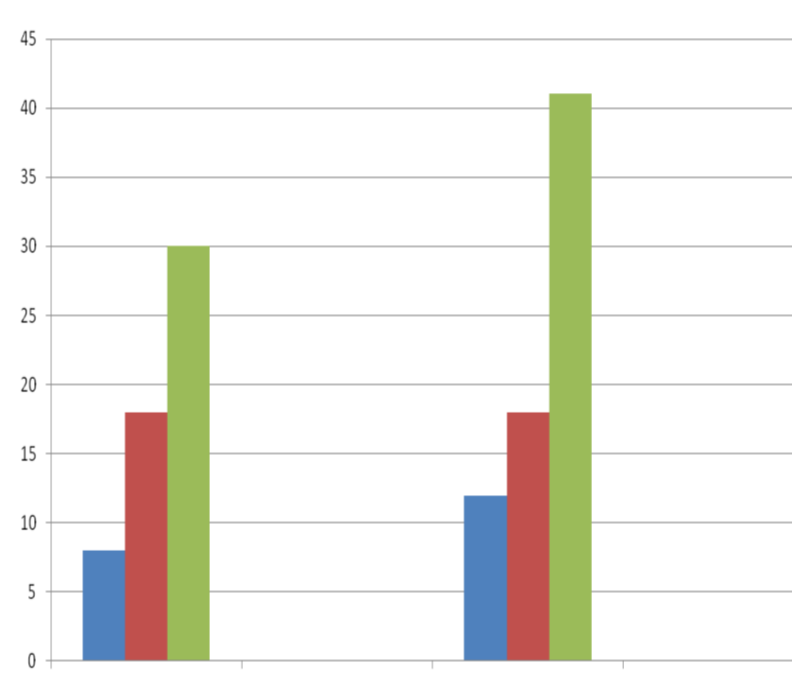
- Health Equalities Framework (HEF)
- Professional Questionnaires
- Daily diaries for patients and carers
- Data base for recording outcomes

### HEF – an outcomes framework

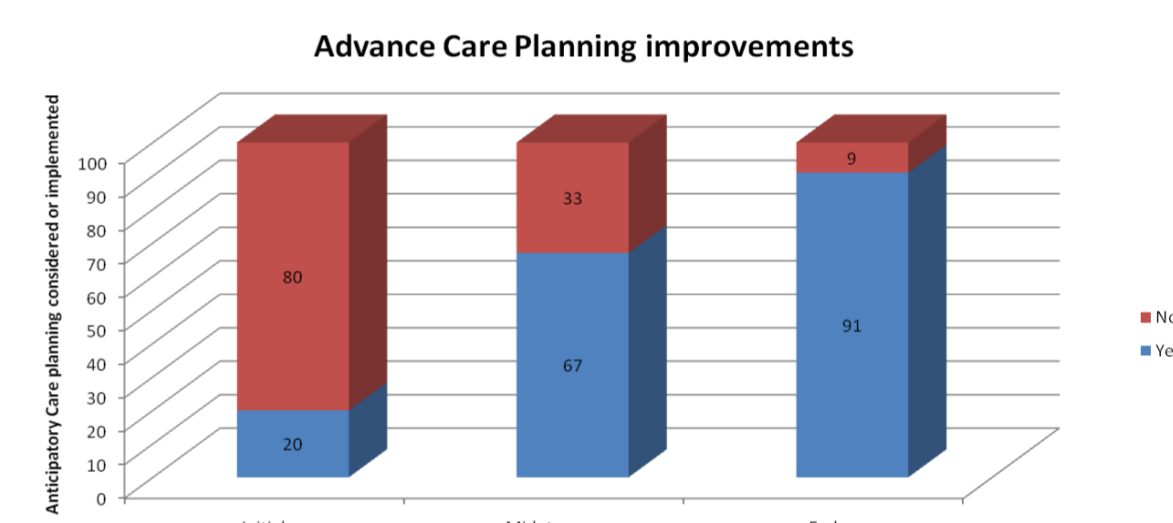


### Questionnaire Results

Inclusion in the Palliative Care and Supportive Care Register



Advance/Anticipatory Care Planning



### “Tree of Life”

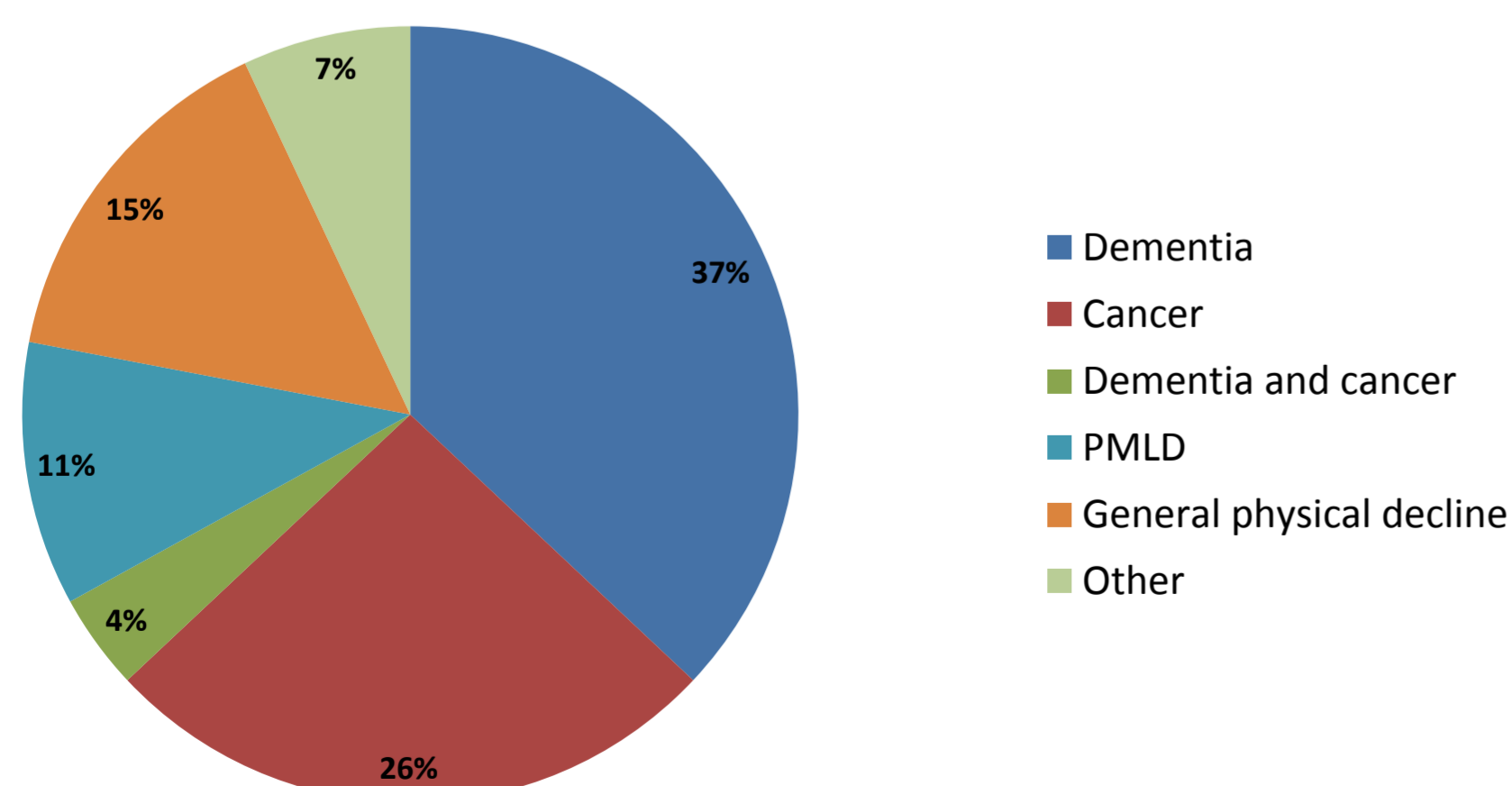
Themes from patient diaries illustrating what was important to them during their journey.



### The Pilot Study

A small pilot study (27 patients) of the Care Pathway was conducted across Greater Glasgow and Clyde and Ayrshire and Arran Health Boards over a 6 month period. The sampling frame was concerned with individuals who had a known LD and were known to adult LD teams and as defined by the World Health Organisation , palliative care needs<sup>3</sup>.

Population Sample :



### Conclusion

The pilot demonstrated that the pathway was easy to follow and effective in assisting practitioners to deliver improved palliative care through partnership and collaborative working.

“ Helped focus on task, giving clear guidance. Helped care staff have a better understanding of process and the need for holistic assessment, future planning and pain management”

### The Future

- Report and recommendations submitted to the Scottish Government for cross policy consideration between LD and PC Advisors
- Continue local development of Key Practitioner roles
- Project leads continuing to facilitate and support this.
- Resources will be made available through the project website [www.ldpcproject.co.uk](http://www.ldpcproject.co.uk)

1. McEnhill L. Widening access to palliative care for people with learning disabilities :guidance and resources for professionals 2013.  
2. The Keys to Life – Improving quality of life for people with learning disability. The Scottish Government, Edinburgh 2013.  
3. World Health Organisation of Palliative Care, 2004. <http://www.who.int/cancer/palliative/definon/en/>.

