**Supporting People with Learning Disabilities through the Palliative Care Journey** Learning Disabilities and Palliative Care: Building Bridges Supporting Care Project The Prince and Princess of Wales Hospice, Glasgow Allison O'Donnell and Liz Smith-Project Leads

## INTRODUCTION

People with learning disabilities (PWLD) frequently experience various barriers in accessing effective and appropriate health care and are often marginalised from mainstream health services.<sup>1</sup> These barriers, coupled with poor understanding of the palliative care role, contribute to difficulties accessing palliative care services.<sup>2</sup> Studies also show that people with learning disabilities have poorer health and die younger than the general population; with life expectancy poorest in those with the greatest support needs and those with the most complex and/or co morbid conditions.<sup>3</sup> Within Greater Glasgow and Clyde (GG&C) it was recognised that staff from both Learning Disability (LD) and Palliative Care (PC) services required support in meeting the needs of this group. In response to this, the award winning project "Learning Disabilities and Palliative Care: Building Bridges - Supporting Care" was established.

With funding from the Scottish Government, The Prince and Princess of Wales Hospice and Help the Hospices (Year 1 only), this project is a working example of partnership and collaborative working. Links have been established at both local and strategic levels within LD and PC services, including all six adult hospices and all LD Teams within the geographical area. The project is led by senior practitioners representing both LD and PC services.







## **DEFINITION OF A LEARNING** DISABILITY

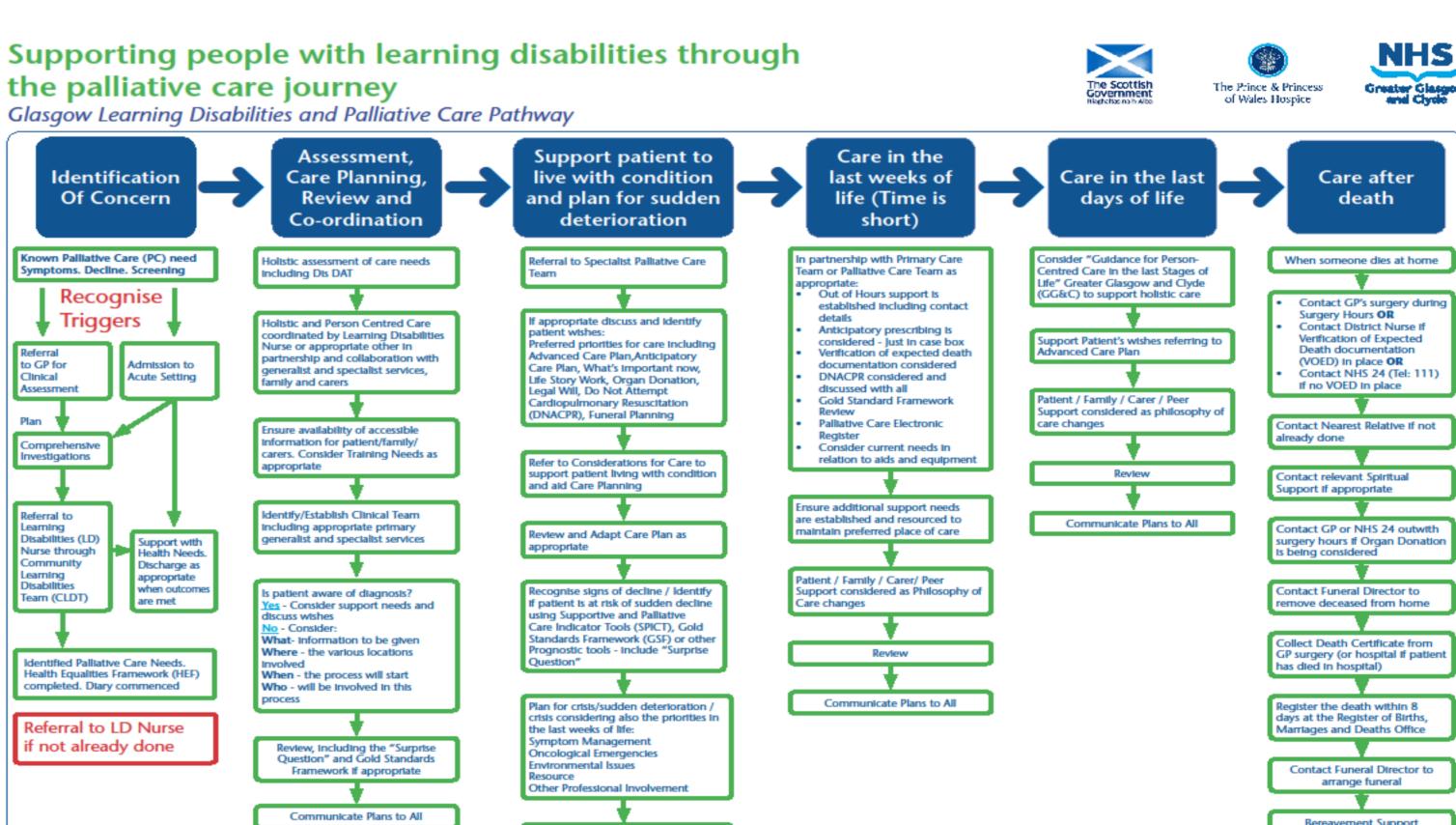
"The presence of significant reduced ability to understand new or complex information, to learn new skills (impaired intelligence); with a reduced ability to cope independently (impaired social functioning) which started before adulthood, with a lasting effect on development." <sup>4</sup>

ACP- "...as a philosophy, promotes discussion in which individuals, their care providers and those close to them make decisions with respect to their future health or personal and practical aspects of care". <sup>5</sup>

The initial focus of this project was to ensure that LD and PC staff across GG&C worked collaboratively and in partnership, developing the skills, knowledge and confidence required to provide high quality and effective palliative care for people with learning disabilities. Subsequently an integrated Care Pathway has been developed. Advanced Care Planning has been embedded within the Pathway and has been a recurring theme in education delivered to staff. The Pathway will be the focus of a Pilot study which will commence in September 2014 for a six month period within GG&C and within Ayrshire and Arran Health Board. Following evaluation, outcomes will be shared nationally.

## **CARE PATHWAY**

Recommendation 26 of the Learning Disability Strategy Keys to Life states that "the Glasgow palliative care pathway is evaluated and rolled out nationally by 2015 to improve the care outcomes for patients with learning disabilities" The Care Pathway has been developed with multi professional commitment from both specialist services, ensuring the holistic care needs of individuals with LD are considered. Underpinned by evidence based practice the pathway is fundamental in promoting the delivery of high quality PC for PWLD. The pathway aims to support practitioners across all health and social care settings to work collaboratively in partnership co-ordinating care throughout the patients journey.





**STAFF SUPPORT** 

Identified ACP Resources in

"Considerations for Care" to support care planning

## **ADVANCED CARE PLANNING** (ACP)



Referral to both generic and specialist palliative care services should be considered early in the patient's journey even if the person has no identified specialist requirements at this time. This allows for proactive advanced care planning including opportunities to consider:

Breaking bad news recognising that PWLD are rarely encouraged to consider issues around loss, death and dying. 

to GP for Clinical

Assessment

Referral to

Community

- Allows PWLD the opportunity to be involved in all aspects of advanced care planning at a pace that supports their intellectual understanding and emotional responses.
- Allows time to plan for reasonable adjustments to be made, improving outcomes and experience
- Allows time for appropriate methods to be established to ensure that people who lack capacity have their best interests taken into account, as and when necessary.
- Allows services the opportunity to prepare appropriate and adequate support throughout the patient journey.





1.Emerson E, Baines S, Allerton L, Welch v, (2011) Health Inequalities and People with Learning Disabilities in the uk: 2011

2.Heslop P, Blair P, Fleming P, Hoghton M, Marriot A, Russ L (2013)Confidential Inquiry into Premature Deaths of People with Learning Disabilities(CIPOLD) 3.Reddall C (2010) A palliative care resource for professional carers of people with learning disabilities European Journal of Cancer Care

4.Department of Health (2001) Valuing People: A new strategy for learning disability for the 21<sup>st</sup> Century.

5.Living and Dying Well: Building on Progress. (2011) p21