

Launch of the Baseline Review of End of Life Care and People with a Learning Disability, their Families and Carers

by

Special Interest Group (End of Life Care for People with a Learning Disability) and End of life Care Team

The need for quality palliative care is well accepted in the general population and is now being driven by the National End of Life Care Strategy (2008). Palliative care should be available to all those who need it. However, the difficulties faced with palliative and end of life symptom control are often very complex and none potentially more so than in the care of people with learning disabilities who may have multiple co-morbidities, complex pre-existing drug regimes and communication difficulties.

There is limited information on the number of people with a learning disability in Shropshire who have used end of life care services. However data is improving with the introduction of registers of people with a Learning Disability in primary care (QOF, 2006/7) followed by the Designated Enhanced Service (2008) offering people with a learning disability an annual health check.

The demographics of death in relation to age, cause of death and place of death has changed radically for the general population over the past century (DH, 2008). There are also changes in people with a learning disability; individuals are now living with families or in community settings. People are living longer and therefore developing long term conditions as seen in their peers.

Diagnostic overshadowing is when the learning disability is seen as the primary problem, without considering other general causes of symptoms that occur and can be easily identified in non disabled adults (Six Lives, 2009) and can lead to stress and inappropriate care as individuals symptoms are put down to their disability and not underlying health or physiological issues.

A special interest working group was set up facilitated by one of the end of life care team the members consisting of people with a learning disability from Taking Part Shropshire & Telford, providers of services, Severn hospice, family carers and Mencap. The group initiated the baseline review and used a variety of questionnaire, focus groups and case studies to capture the information from GP Practices, community teams, community hospitals, residential and nursing homes Severn Hospice, families, paid carers and joint community learning disability teams

Aim of the baseline review

- To identify key themes and issues for professionals when working with people with a learning disability with end of life care needs
- To acknowledge and share good practice in current End of Life Care and motivate staff to continue to improve care
- Re-energise, inspire staff and address attitudes, values and beliefs about dying and death and increase staff confidence and commitment to doing this well for people with a Learning Disability

- To make recommendations for service improvement in End of Life Care for people with a Learning Disability for 2009/10

The launch was attended by 32 staff from organisations across Shropshire and Telford & Wrekin. The half day session were divided into short presentations from the special interest group giving an overview of the work. There was excellent feedback from members of this group and from the Taking Part Advocacy group Shropshire & Telford. The honesty and clear way that Marlene, Gaynor and Julie Ann spoke was a privilege to listen to about the way they felt about being involved in this work, how they had no understanding of the process of death and dying and how they were treated by society when someone in their family died. How people with learning disabilities are perceived by others, the lack of respect given to them when someone close to them dies and the life long impact that this can have was demonstrated They gave an overview of their role in the special interest group and their contribution to the baseline review, they shared their experiencing of visiting both Seven Hospice sites. The visits were held last year which were facilitated by Sharon Hicks and Bobby Mansell who work at the hospice.

The good practice guidance produced by Mencap: Living and dying with dignity: *Helping people with a learning disability receive inclusive end-of-life care services* was shared this is available from www.mencap.org.uk/endoflifecare This contains a useful checklist for positive practice which can be used by all organisations providing services for people with a Learning disability The morning was rounded up by some group work on an action plan from the recommendations from the work.

One of the groups networking



Some comments received on the evaluations were:

"We must always continue to listen to the voices, fears and wishes of these people we support to empower all life choices"

"It has certainly made me realise that I need to re-visit this subject with certain individuals"

"It has made me realise that "inclusion" isn't a reality but with info/inter-professional networking this will become a reality.

This has made me think about current practice and ways we can provide better service in future

"I thought it was an excellent day for networking and the discussion generated by Taking Part was one of the highlights. It really helped that the day was very informal and the programme was flexible as that allowed for discussion. The mix of people attending was invaluable and one of the best opportunities for networking I've experienced"