



Champions for learning disabilities

Enable Care and Home Support – End of Life Project

Developing training for end of life care has led to an empowered staff team and more engaged residents and people who use the service.





Background

Enable Care and Home Support (part of Enable Group) provides services for 350 people with learning disabilities. This includes supported living, day services, residential and nursing care. They provide a range of packages for up to 24 hour nursing care. Services are mainly in Derbyshire and surrounding areas and some of it is registered provision.

In 2011, Enable bid for some funding as part of the Skills for Care End of Life (EoL) project. Kim Maddison, the team leader in one of the nursing homes, had done a palliative care course and wanted to take it further. Also they had started some work with a homes' educator from the Macmillan team and were considering applying for the Life Enhancing Care Home Award.

Aims

The project aims were to:

- identify gaps in standards in relation to people with learning disabilities
- develop and deliver a training programme based on the standards
- develop staff knowledge, skills and understanding in EoL care
- achieve the Life Enhancing Care Award.

What was done?

The gaps identified in the standards were in diagnostic overshadowing and disenfranchised grief. Staff working with people with life limiting conditions attended the training sessions.

The resources and training have been used and developed in the services. Kim's role in providing the training has enabled her to develop her leadership and motivational skills and qualities. As well as continuing her role as team leader, she also now works two days across the whole organisation providing training, supporting all staff working with end of life care and a champions group.

The staff have been so enthusiastic about having champions and mini-champions for end of life that they have developed it in a range of work across all the houses. Although the champions work in different houses they are supported as a team. They have mini-champions for autism, health promotion, information, dignity, fundraising, person centred working and epilepsy. For autism and health promotion there are two support workers for each and they meet with health colleagues to develop strategies.

The staff have involved service users and families in developing EoL practice. Some of the changes have come from looking at the original assessment and using different tools eg using the Abbey pain scale, originally for people with dementia, which uses facial expressions. By using new tools, it means there is evidence to take to GPs about the levels of pain control required.



Outcomes

Practice areas that have developed are:

- better involvement of service users and relatives in planning and assessment
- using DisDat forms—disability distress assessment tool
- all residents now have advanced care plans
- trying to get equal access to health services for people with learning disability
- considering privacy and dignity
- having meetings for champions.

The improvement in staff confidence has enabled them to challenge hospital practice in a proactive way. This led to meetings with matrons and the medical director who said they wanted to work in partnership and acknowledged the lack of expertise with people with learning disability. Consequently, Enable staff were involved in the recruitment and selection of the Learning Disability Education Matron at the hospital. There has been an open day at the hospital for service users and carers to find out what has been working well and what not so well. All the local hospitals have now got a learning disability toolkit and a video about communicating with people with learning disability.

Enable staff have also been involved with a number of regional events. They have achieved recognition from Derbyshire PCT on EoL, won a bronze award from Derbyshire County Council for dignity and respect and the Life Enhancing Care Award. Kim won the regional award for frontline leader at the Great British Care awards for her work in end of life.

Joint working and networking is now part of everyday working, with good links with the Macmillan team and with GPs. Staff now go straight to Kim and her team for advice and everything works much better. They have developed an ethos which focuses on developing and building on staff strengths. The team works better together as they have developed shared visions and goals.

The outcomes of the project have now become embedded in Enable services, with the objective to provide person centred end of life care to all residents, as appropriate.

Impact

The impacts from the project are significant:

- residents are receiving more treatments earlier, with better assessment and prognosis. Use of different assessment tools has resulted in better pain management and prolonging life in a quality way
- since the project, several residents have been cared for and died at home rather than in hospital. These have been mainly older people in their 80s and 90s, but also some people with complex health issues
- there is better working with palliative care and health staff in the hospitals. The hospital has appointed a learning disabilities matron with the role of increasing awareness across the hospital and Kim is part of the project team taking it forward.
- the champions and mini-champion roles have resulted in good practice being cascaded through the services



there is now a great passion for the work and people seem prepared to work beyond what would normally be expected, eg spending their own time doing health action plans
quality of life has been improved for service users, with more understanding of conditions and people with learning disability are being treated more like everybody else
Kim's nursing home held a meeting with carers and families to find out what they thought was working well and what could be done differently. The families couldn't give any examples of what could be done better, which would not have been the case a year ago.

“It is wonderful to see service users smiling. At best interest meetings before, we would have struggled to get them to participate, but now we take a different approach by recognising their expertise and working with them. As a result they feel listened to and feel they have choices. From a manager's point of view it has been wonderful to see staff flying and we have been very grateful to have had the experience of being involved in the Skills for Care project. It feels as though talent has been liberated and the organisation has found a hidden resource that it can tap into.” Lesley Montisci, Assistant Director for Registered Care.

The training and the process of integrating person centred, EoL practice has continued. It has had a great impact on the culture of the homes, the confidence and motivation of the staff and has led to plans to do much more work with other partners including local hospitals. Better dialogue and understanding with the hospital has meant better transitions when residents have needed to go in and out of hospital. It has also avoided hospital admissions and service users died at home rather than in hospital. In the past, it is unlikely that this would have happened.

Avoiding hospital admissions

Two service users with learning disability, who have been in supported living accommodation, have been diagnosed with dementia. By training the staff in end of life care, they have been able to keep the service users in their home environment.

Another example is of a young woman who died very recently. The GP wanted her to be admitted to hospital but her mother did not want this. It was agreed that she would go to hospital for assessment of her condition and if end of life care was required she would come back to the home. This is what happened and afterwards her mother contacted the home to say she was so grateful and very satisfied with her care.

Learning

Key learning points include:

- whilst resources across a range of organisations are being used more effectively to provide better quality end of life care for people with learning disability, it needs people like Kim and the other champions who are motivated and have the passion to take it forward. It is very hard to put a price on this
- staff are the most important resource and once they are empowered to see the difference they can make to people's lives it motivates them to do more



- Enable has been able to see how the standards and tools can apply to other areas of practice such as dementia. Critiquing the standards has been a good way of learning and developing knowledge that underpins practice
- educating people about end of life care is very important. Despite the great strides that have been made at Enable there are still taboos. Even the most skilful of trainers, like Kim, still meet resistance and some people find it very uncomfortable to discuss. Therefore it has to be an ongoing process to overcome the barriers
- the process of developing a programme that meets the needs of the organisation and considers the implication of the service user group is important, even though nationally there are good resources available
- the idea of mini-champions came from staff but Enable are going to drop ‘mini’ and just use champions since it should not matter what position people have—if people have talent and enthusiasm it should be nurtured
- Enable has learnt it is important to be inclusive and to involve friends and family. There is always something that can be done to help people make quality choices
- leadership and having a can do attitude are essential to a good service.

Next steps

Enable are now planning to:

- hold development days for staff across all registered care to think about champion roles and how to further utilise the skills and interests of staff
- develop other services, such as intermediate care and rehabilitation
- continue to develop partnership working with trusts, GPs, hospices and other organisations
- continue to develop tools with, and for, service users.

Contacts

www.enable-group.org.uk

Further information

For further information about the health and social care integration work between Skills for Health and Skills for Care please contact:

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