

# LEARNING DISABILITY AND END OF LIFE CARE COMMUNITY COLLABORATION PROJECT



**Background:** People with a learning disability are three times more likely to die at a young age than the overall population. Furthermore, they may experience inadequate end of life care through providers not recognising or considering individual needs.

In September 2017 Mary Stevens Hospice appointed two learning disability champions, as part of the strategic vision to support and provide specialist palliative care for more people from marginalised and seldom heard groups.

## Project Aims

Increase accessibility for people with learning disabilities to receive good, equitable and coordinated end of life care.

Identify gaps in knowledge, educate Mary Stevens Hospice employees and volunteers across clinical and community trading sectors.

Dispel hospice myths, breaking barriers between palliative care and learning disability health and social care services.

Collaborate and engage with learning disability workforce, plan for future care and identify training needs in Dudley.

## Methods

Peer review of hospice services conducted by a self-advocacy group

Community engagement with day centres, care homes, care associations, advocacy groups and health care professionals.

Presentations delivered to providers, explaining objectives of project.



*"Mary Stevens Hospice are tackling such an important subject, in such a sensitive way. This is long overdue."*

*"...they are true learning disability champions, passionate and committed about getting the service right for everyone."*

*"The hospice is already a friendly place and I see it getting more disability friendly."*

*"It was great to meet you and hear about the great work you are doing in the community....the work you and Mary Stevens Hospice are doing to try and improve access to medical services and palliative care, which I think is extremely important, particularly for people with learning disabilities or mental health problems."*



## Outcomes and Future Plans

Identification of gaps in knowledge and resources at Mary Stevens Hospice, information pack produced and training for staff and volunteers September 2018.

Review of available literature for patients and carers, specific easy read material available with plans of producing further information, bespoke to hospice and Dudley.

Easy-read pictorial signs installed in In-Patient Unit, with protected funding allocated for signs for future hospice developments.

'Wish list' consisting of sensory equipment, computer software and resources in place.

Champions trained in Makaton method of communication, resource and symbol books available, further plans for more staff to attend Makaton training.

In-Patient Unit, Day Services and Fundraising buildings recognised and rewarded on 'Dudley Safe Place' scheme, for people with a learning disability, autism or dementia.

Collaboration with learning disability providers resulted in co-hosting Dying Matters Awareness Week events.

Partnership with Birmingham City University, developing initiatives and research proposals around diversity and inclusion, ongoing strategy to develop West Midlands network.

Considerations regarding introducing learning disability student nurse placements at hospice.

24 learning disability care home staff attended and supported by hospice care home team to be recognised as 'Palliative Care Champions.'

End of life education workshops booked for November 2018 for 30+ people from learning disability organisations.



## Conclusion

One of Mary Stevens Hospices top priorities is to provide care for more people. We want to continue expanding on the work that we do, identify and offer support to more people who need it in our community, ensuring nobody is disadvantaged at end of life.

Our values are simple; care, compassion and kindness.

Unfortunately, those whose needs are most often unnoticed at end of life are of those who are unable to advocate for themselves. The learning disability champion project will continue improving and addressing inequalities vulnerable groups experience, supporting people, and those important to them to have a good quality of life, including the final hours of life.

## References

- 1 Heslop P, Blair P, Feleming P, Hoghton M, Marriott A and Russ L (2013) Confidential Inquiry into premature deaths of people with learning disabilities (CIPOLD): Final report. Bristol: Norah Fry Research Centre, University of Bristol.
- 2 Care Quality Commission, A different ending Addressing inequalities in end of life care. Online [www.cqc.org.uk/news/stories/different-ending-our-review-looking-end-life-care-published](http://www.cqc.org.uk/news/stories/different-ending-our-review-looking-end-life-care-published)