



Palliative care and people with learning disabilities: Recognition and assessment (2)



Early recognition

When caring for or supporting someone with learning disabilities who is subject to palliative and end of life care, if you notice any changes in their presentation, it is important that you take responsive action.

SO Stop and think...

- Is this a new symptom?
- What could this be?
- Seek out medical support – GP and healthcare professionals involved in the persons care
- We know that often illness and diagnosis is late as it overshadowed by the individuals learning disability

Assessment

- It is vital to ensure a holistic assessment, which focuses on the individual needs of the person you are supporting or caring for. This is likely to change over time so should not be seen as a one-off event. It is an ongoing process that must actively engage the individual and others involved in their care. As part of this it will important to link in with any existing assessments but also to review what might have changed and who needs to be involved?
- There are lots of different assessment tools available but the most important thing to do is to undertake a baseline assessment so that everyone involved understands the individual and how their needs. E.g. how they communicate, any known stress triggers, their likes and dislikes etc. All of this can greatly assist any new members of staff supporting the individual .
- Check for Hospital Passport, One Page Profile or individualised communications systems to make sure they are all updated.

Recognising the dying phase

This can be challenging and why it is so important to know the person.

- Check for any reversible causes e.g urinary tract infections
- What changes have you noticed e.g Is their condition deteriorating day by day or hour by hour?
- Is the person less responsive and less able to communicate?
- Is there changes in their breathing pattern?
- Changes to appetite/ drinking patterns?
- Has the persons mobility declined?
- Consider the persons individual need including cultural and spiritual factors
- If the person lacks capacity, decisions must be made in their best interests

For more information, please visit:

<https://www.nhs.uk/conditions/end-of-life-care/changes-in-the-last-hours-and-days/>

Top tips!

Speak with the person/ people who know them well

Share information with palliative care colleagues

Useful websites

<https://www.bild.org.uk/wp-content/uploads/2020/01/Improving-End-of-Life-Care-for-LD-Jan-2019-FINAL-1.pdf>

www.mencap.org

<https://www.skillsforcare.org.uk/Developing-your-workforce/Care-topics/End-of-life-care/End-of-life-care.aspx>

<https://www.mariecurie.org.uk/professionals/palliative-care-knowledge-zone/final-days/recognising-deterioration-dying-phase>

<https://www.nice.org.uk/guidance/ng31/chapter/Recommendations#recognising-when-a-person-may-be-in-the-last-days-of-life>

[https://www.stoswaldsuk.org/how-we-help/we-](https://www.stoswaldsuk.org/how-we-help/we-educate/education/resources/disability-distress-assessment-tool-disdat/)

[educate/education/resources/disability-distress-assessment-tool-disdat/](https://www.stoswaldsuk.org/how-we-help/we-educate/education/resources/disability-distress-assessment-tool-disdat/)

<https://www.goldstandardsframework.org.uk/>

For further information please visit: www.learningdisabilitynurse.co.uk