Physical health considerations for individuals with learning disabilities

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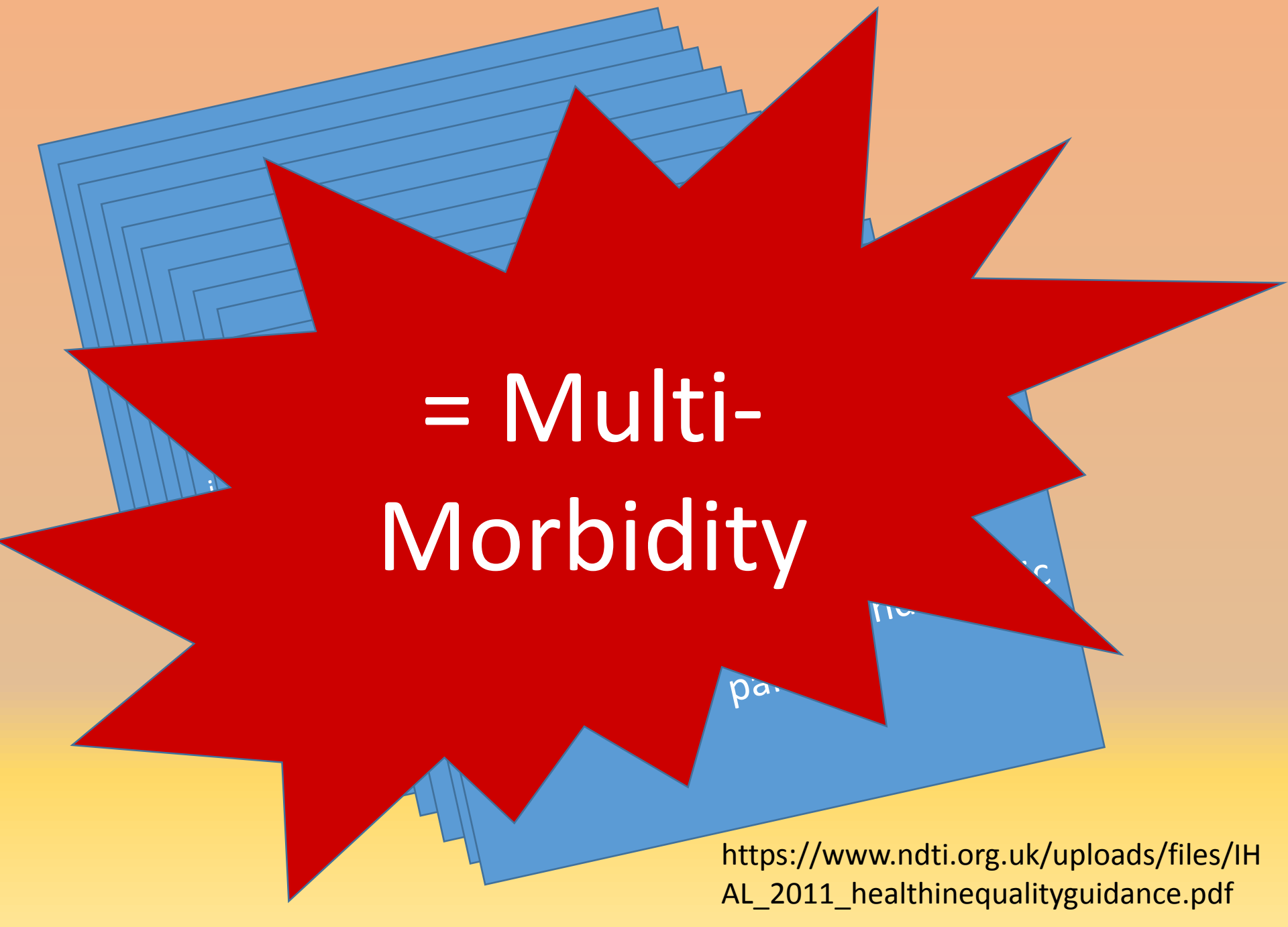
Physical Health and People with Learning Disabilities

- Prevalence rates across key physical health problems
- Determinants of increased risk
- Current national strategies and models of good practice
- Physical health and psychological wellbeing

Prevalence rates of Physical Health Difficulties in People with Learning Disabilities

What might be some of the physical health difficulties that people with learning disabilities are more likely to experience/have additional difficulties with?



https://www.ndti.org.uk/uploads/files/IHAL_2011_healthinequalityguidance.pdf

Multi-Morbidity Study: Kinnear et al (2017)

- Sample of 1023 people with LD
- 98.7% had two or more conditions
- Approx. 90% had 6 or more
- Mean number of physical health conditions was 11 (highest was 28)
- Five most commonly occurring conditions were visual impairment, obesity, epilepsy, constipation and ataxic/gait disorders
- Complexities include drug–drug interactions, drug–disease interactions and disease–disease interactions.

Kinnear D, Morrison J, Allan L, et al ***Prevalence of physical conditions and multimorbidity in a cohort of adults with intellectual disabilities with and without Down syndrome: cross-sectional study***
*BMJ Open 2018;**8:**e018292. doi: 10.1136/bmjopen-2017-018292*

Determinants of Physical Health Difficulties for People with Learning Disabilities

Research has suggested 5 broad classes of determinants:

1. Specific Genetic and Biological Causes
2. Increased exposure to 'Social Determinants'
3. Access and quality of provision
4. Communication and health 'literacy'
5. Personal health risks and behaviours

http://webarchive.nationalarchives.gov.uk/20160704145615/http://www.improvinghealthandlives.org.uk/index.php

1. Specific Genetic and Biological Causes

Many Genetic/chromosomal are one of the key causes of learning disabilities. Many conditions/genetic causes remain under/un-diagnosed

Many of those which are known predispose people with learning disabilities to physical health problems,

e.g.:

Down Syndrome: thyroid problems, sensory problems, heart problems, dementia, coeliac disease, diabetes.

Williams Syndrome: heart problems

DiGeorge syndrome (22q11 deletion): cleft lip/palette, congenital heart disease, hormone problems, bone muscle and joint problems, speech and hearing problems

Cornelia de Lange: Respiratory problems, heart defects, sensory problems, reflux, musculoskeletal problems, seizures

2. Increased exposure to 'Social Determinants'

- Poverty
- Poor Housing Conditions
- Unemployment
- Social Disconnectedness
- Overt Discrimination

- It has been estimated that increased exposure to low socio-economic position/poverty may account for 20–50% of the increased risk for poorer health and mental health among British children and adolescents with learning disabilities

3. Access and quality of provision

- Harder to access assessment and treatment/lack of appropriate services
- Physical barriers to access
- Failure to make reasonable adjustments
- Lack of expertise amongst healthcare staff
- Diagnostic over-shadowing

Identifying the factors affecting the implementation of strategies to promote a safer environment for patients with learning disabilities in NHS hospitals: a mixed-methods study (Tuffrey-Wijne et al., 2013)

- The study aimed to identify factors in NHS hospitals that helped promote a safer environment for patients with learning difficulties and well as those factors that compromised this.
- 21 month study involving 6 NHS hospitals in the south of England.
- Participants: staff, patients and carers
- Mixed methodologies – questionnaires, surveys, interviews, observations and monitoring adverse events and complaints.

3 stages:

- Stage 1 – Within each hospital they mapped the systems and structural changes put in place to promote the safety of patients with learning disabilities.

- Stage 2 – Examined the efficacy of the measures in place.

- Stage 3 – Examined the applicability of the findings to other groups of vulnerable patients (e.g. people with dementia and those with mental health problems).

Results

Examples of initiatives to improve care for patients with learning difficulties across all hospitals. These include:

- learning disability hospital liaison nurses
- patient held health records
- carer polices.

Safety concerns included:

- delays in care
- omissions of basic care
- omission of treatment.

Barriers to safer care

- Problems with identifying patients with learning disabilities within hospitals.
- Lack of understanding regarding the support needs of people with LD and reasonable adjustments that may be required.
- Lack of knowledge of the Mental Capacity Act and lack of confidence in its application.
- Expertise of carers not always recognised. Basic care not always provided due to the assumption that this was being provided by carers.
- Lines of responsibility and accountability for the care of people with the LD not clear.

4. Communication and Health 'Literacy'

- https://www.youtube.com/watch?v=8wdwAP3auQU
- Difficulties in understanding/communicating pain experience
- Reliance on carers to identify health needs
- Lack of experience/knowledge of healthy lifestyle choices
- www.easyhealth.org.uk

5. Personal Health Risks and Behaviours

- Diet
  - Less than 10% of adults with learning disabilities in supported accommodation eat a balanced diet
- Exercise
  - Over 80% of adults with learning disabilities engage in levels of physical activity below the Department of Health's minimum recommended level
- Substance Use (Taggart, 2006)
- Sexual Health
- Weight
  - much more likely to be either underweight or obese

Personal Health Risks and Behaviours

Exploration of body perception and body dissatisfaction in young adults with Intellectual Disability

Eden and Randle-Phillips (2017)

- Young adults with LD tend to hold positive beliefs about their bodies.
- Females with LD are likely to perceive their bodies to be smaller than they are
- Neither males nor females report a desire for an altered body size.
- Individuals with LD understand what is meant by 'overweight', 'healthy-weight' and 'underweight' although these concepts are qualitatively different compared to those held by people without ID. Furthermore, individuals with ID are unable to apply these body size categories to themselves.
- This mirrors observation by Taggart (2006) in the field of substance abuse and LD who suggested that people with LD may not be motivated to change their behaviour as they may not see that they have difficulties

Responses to the poor physical health of people with learning disabilities

Confidential Inquiry

Confidential Inquiry into Premature Deaths of People with Learning Disabilities (June 2010 - May 2012)

Looked at:

- why people with learning disabilities die early and what could be done to prevent this
- the care and support people with learning disabilities have received, what has worked well and what could be improved
- the care and support of people with learning disabilities compared with that of people without learning disabilities
- identifying good practice

Confidential Inquiry

Results

- Deaths of 247 people with LD reviewed.
- Around 2 ½ times the number of deaths anticipated.
- Median age of death for men with learning disabilities was 65 (UK population 78) 13 years younger than gen. pop.
- Median age of death for women with learning disabilities was 63 (UK population 83) 20 years younger than gen. pop.
- Most common underlying causes of death for people with LD were heart and circulatory disorders (22%) and cancer (20%). Similar pattern to general population.
- Respiratory infection was the most common immediate cause of death for people with LD.

Confidential Inquiry

Results continued

- 42% of 238 deaths were identified as premature deaths – ‘without a specific event that formed part of the “pathway” that led to death, it was probable (i.e. more likely than not) that the person would have continued to live for at least one more year’.
- In 86% of cases it was identified that the person was unwell and help sought from a health professional.
- Delays or problems with finding out why the person was ill and delays or problems with treatment were the most frequent reason for deaths being considered premature.
- 27.5% of deaths considered amenable to change with good quality healthcare.

Confidential Inquiry

Recommendations

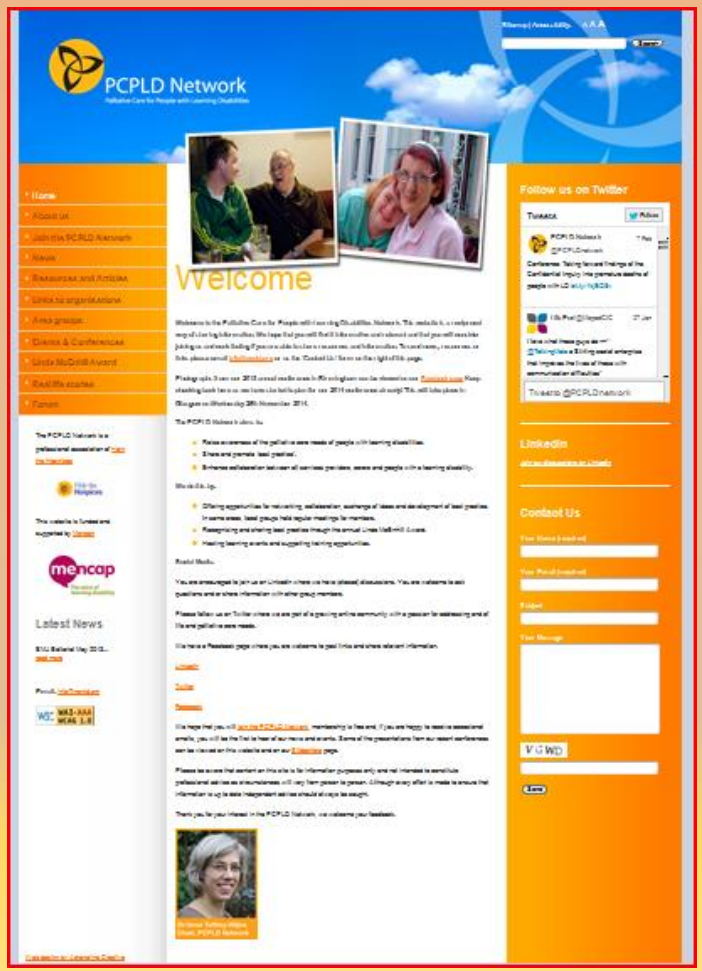
- Access to 24 hour advice on Mental Capacity Act (MCA)
- Clarification around definition of Serious Medical Treatment
- Mandatory MCA training and updates for health and social care staff
- DNACPR guidelines to be standardised and clarified
- Advanced health and care planning to be a priority
- Decisions that a person is to have palliative care only need to be supported by the MCA if the person lacks capacity to express their views. Referral for specialist palliative care.
- National LD mortality data to be routinely collected and reviewed
- Local LD mortality data to inform local Health and Wellbeing board priorities as well as needs-based commissioning
- Creation of National LD Mortality Review Body

National LD Mortality Review Body

- Latest Annual Report:
- https://www.hqip.org.uk/resource/the-learning-disabilities-mortality-review-annual-report-2018/#.XeaLMG52uYM

- Finding show steady improvement in care since the confidential enquiry, but inequalities continue to exist

Palliative Care for People with Learning Disabilities (PCPLD) Network – http://www.pcpld.org



Directed Enhanced Service: Annual Health Checks

Since 2008 the Department of Health has required PCTs to offer GP practices in their area the opportunity to provide annual health checks for people with learning disabilities as part of a DES scheme.

CLDT's have been key partners:

- Training GP practice staff
- Maintaining database of service-users
- Informing service-users
- Monitoring non-attendance

Reasonable Adjustments for People with Learning Disabilities

- Reasonable adjustments Guidelines: https://www.gov.uk/government/collections/reasonable-adjustments-for-people-with-a-learning-disability

- Blood tests
- Cancer screening
- Constipation (www.apictureofhealth.southwest.nhs.uk/wp-content/uploads/healthy-life-styles/diet/What_Is_Constipation.pdf)
- Dysphagia
- Obesity and weight management
- Oral care
- Postural care
- Preventing falls

Reasonable Adjustments for People with Learning Disabilities

- Longer appointments
- Easy read information: Before, during and after
- Additional communication aids
- Awareness of diagnostic over-shadowing
- Being person-centred
- Importance of consideration of capacity

The psychological impact of diabetes for people with learning disabilities

Why study illness perceptions?

- A person's own judgements and perceptions about their illness are key influences in outcome.

Why study the illness perceptions of people with learning disabilities?

- Often excluded from 'mainstream' research
- Continued diagnostic overshadowing
- How do we know what might be the same/different?

The psychological impact of diabetes for people with learning disabilities

- Diabetes is a significant health problem amongst people with learning disabilities (both T1 and T2) (mean estimate 9% as compared to 4.5%)
- Two recent systematic reviews identified 13 and 17 studies looking and diabetes in people with LD (McVilly et al, 2014; Taggart et al, 2014)
- Reviews highlighted that:
  - Optimum care is not achieved for many people with LD
  - Diabetes management in LD should be a priority for policy makers and healthcare professionals

The psychological impact of diabetes for people with learning disabilities

Results

6 super-ordinate themes:

Understanding diabetes
Physical Effects of diabetes
Difficult relationship with diabetes
Support with diabetes
Social Impact of diabetes
Multiple health difficulties

The psychological impact of diabetes for people with learning disabilities

Results

6 super-ordinate themes:

'I'm not sure if I'm going to have it for the rest of my life'

1. **Understanding diabetes**
   - ▶Use of language related to diabetes
   - ▶Confusion / Uncertainty about diabetes

2. **Physical effects of diabetes**
   - ▶Fluctuating State
   - ▶Effects of living with diabetes

How Do People with learning Disabilities and Diabetes Experience and Perceive their Illness?

3. **Difficult relationship with diabetes**
   - Frustration with illness regime
   - Struggle with adherence
   - Preparation and Planning
   - Diabetes as tolerated
   - Diabetes as unwanted

'I don't and I still don't like needles … but now I'm older I'm getting used to it, and I know I've got to do it to save my life'

The psychological impact of diabetes for people with learning disabilities

'I can be a bit forgetful sometimes, or sometimes I might not take it because I'm bored, or when I get depressed"

Well, I just think that people, people's got to learn to cope with it, and try and take the right medication and get their selves checked out, whenever they're at the doctor, and try and eat healthily and all that ... and exercise and everything to stop them from getting ill, and do a better job than what I've been doing'

The psychological impact of diabetes for people with learning disabilities

4. Support with diabetes

- ▶Support from others
- ▶Struggle with need for support

5. Social impact of diabetes

- ▶Diabetes as socially undesirable
- ▶Comparison to others
- ▶Importance of social interaction

'I feels a right idiot when I've got people watching me and they're watching the football and I'm doing it in my stomach … I feels a bit of a prat really'

The psychological impact of diabetes for people with learning disabilities

'I've got fed up not being the same as other people'

'I try to buy the right stuff, to stop me going down to get … I don't get that much chippies and things. Mainly because I know the person down there, so I go there for if she needs a hand, or I go there for the company'

The psychological impact of diabetes for people with learning disabilities

6. **Multiple health difficulties**
   - Multiple health difficulties
   - Relationship with other health difficulties

     - Epilepsy
     - Irritable bowel syndrome (IBS)
     - Depression
     - Visual impairment
     - Asthma
     - Restricted mobility

The psychological impact of diabetes for people with learning disabilities

6. Multiple health difficulties

… that's why I get fed up sometimes with eating. I won't eat or just a sandwich or something. I won't bother eating anything 'cause I'm always getting interference from the IBS side of it as well'

'Cause of the pain. 'Cause its no good going outside when you've got pain in your knee'

The psychological impact of diabetes for people with learning disabilities

SUMMARY

- Similar themes to general population research (i.e. confusion, challenges to self/identity, social impact)

Additionally

- The difficulties in understanding and living with diabetes may be exacerbated for people with learning disabilities owing to
- limited cognitive ability,
- Increased need for support
- existing identity conflict as a result of stigmatisation due to LD.
- Multiple health difficulties

The psychological impact of diabetes for people with learning disabilities

CLINICAL IMPLICATIONS

- Effects of negative appraisal/illness perceptions and how to work with this
- Impact on emotional well-being
- ? How might symptomatology of this be different for people with LD?
- Motivation to change behaviour
- Working with multiple complexities (e.g. LD and physical health/emotional and physical/multi-morbidity)

Conclusions/Reflections

- Despite people with learning disabilities being predisposed to many health conditions there is much than can be done to overcome physical and social barriers to healthcare

- Currently there continues to be a lack of ‘first-person’ research on the personal experiences of people with learning disabilities and how these might be the same or different. This could add significantly to successful, person-centred interventions

Thank-you

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