OXFORD DEANERY LEADERSHIP FELLOW PROGRAMME:

LEADERSHIP FELLOW IN
END OF LIFE CARE &
LEARNING DISABILITIES :

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ACKNOWLEDGEMENTS

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4) **Jane Knowles** - CTPLD Community Lead, Bracknell: for your constant support and providing me with insight into the local LD set-up!

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PROJECT AIM: TO PERFORM A NEEDS ASSESSMENT ON HOW PEOPLE WITH LEARNING DISABILITY CURRENTLY ACCESS END OF LIFE CARE IN THE EAST BERKSHIRE AREA?

CONTEXT/BACKGROUND:

The national estimate for people with known learning disabilities in the UK is currently 1.4 million, and this is estimated to increase. The total population within the South Central Strategic Health Authority is of 9,938, 10% of which are within the East Berkshire area. Listed below are some of key documents, which highlight the national importance of work looking at healthcare needs for people with learning disabilities and specifically at end of life care in these people.

- Healthcare services for people with learning disabilities a key priority for 2009-2012:
  a) ‘Healthcare for all’ an independent inquiry by Sir Jonathan Michael following ‘Six Lives’ & ‘Death by indifference’ report
  b) Recommendations by Sir David Nicholson June 2008 to all NHS & strategic health authorities to ensure services make reasonable adjustments for people with learning disabilities.
  c) Valuing People Now- Jan 2009, commissioning of services, & reducing inequalities
  d) Health action planning & health facilitation for people with LD- a good practice guide

The estimated annual death rate in the UK is ½ million, which is thought to continue to increase. There is estimated to be an increase in the number of people with learning disabilities, and thus the overall proportion of the total population with learning disabilities will be higher! People with learning disabilities are more likely to experience additional health problems compared to the general population, and are likely to have unidentified health needs. Identifying who they are, the numbers of people with learning disabilities & their healthcare needs, will enable the commissioning of adequate & appropriate services throughout stages of life and at the end of life!

Cancers are becoming more common, and the profile of cancers is different in people with learning disabilities e.g. higher incidence GI cancer in people with LD compared to the general population. However they have lower rates of cancers of the lung, prostate, breast & cervical cancers. The incidence of cancer differs 13% in people with learning disabilities compared to 26% within the general population. There is a low
uptake of cancer screening e.g. prostate and cervical, in those with learning disabilities, and a lack of awareness around self examination, and unrecognised prostate problems (incontinence may often be blamed). Some of the barriers which prevent people with learning disabilities accessing appropriate end of life care include e.g. communication - physical inability to communicate/ sensory impairment - visual or auditory, failure / late diagnosis of cancers or terminal conditions - challenging behaviours presumed to be due to learning disabilities, diagnostic overshadowing (physical symptoms presumed to be due to learning disabilities) and presumed quality of life. One of the fundamental issues in end of life care is addressing symptom control. Developing tools to help identify these symptoms - eg DISDAT for pain/distress will help address this need, personalised Health Action Plans for all to include decisions re: end of life care , resuscitation decisions, preferred place of care will help enable patient choice. Anticipating situations where patients may require help with consent/ capacity issue- involving carers, CTPLD, IMCA(advocate) early on- see Case 1 below.

Valuing people now- A new 3 year strategy for people with learning disabilities, published in Jan 2009, sets out the government’s response to the healthcare for all and independent inquiry. Better health for people with learning disabilities, being a KEY PRIORITY. There is evidence these people have poor health and are likely to die at a younger age. Access to NHS is poor, there is a need to achieve full inclusion of people with learning disabilities in the mainstream NHS work, to reduce health inequalities and to ensure high-quality specialist health services where these are needed. Aims to address recommendations from healthcare for all report, namely:

a) Having greater choice and control over their lives & have support to develop person centred plans
b) Get the healthcare they need & the support they need to live healthy lives

CLINICAL IMPACT:

A large part of my needs assessment, was based on finding out about the current network of services that exist within the locality, to identify those with learning disabilities and subsequently manage their healthcare needs. I have concentrated on the following aspects:

a) How to identify population with learning disabilities?

b) Who looks after them- GP, secondary care, carers, CTPLD, other?

c) Where are the gaps?

Patients with learning disabilities must satisfy following 3 components in order to be classified as having LEARNING DISABILITIES DoH definition:

[I] Impairment of Intellectual Functioning:

White Paper 2001 definition, British Psychological Society (BPS) 2001 recommends using WAIS-III UK (Wechsler Adult Intelligence Scale, 1999) to determine IQ via psychometric assessment- see appendix A. This is normally performed by psychologists, once patients have been referred to the CTPLD. Listed below are the varying severities of learning disability.

CLASSIFICATION OF LEARNING DISABILITY AS PER ICD-10:

<table>
<thead>
<tr>
<th>Level</th>
<th>IQ Range</th>
</tr>
</thead>
<tbody>
<tr>
<td>PROFOUN</td>
<td>&lt;20</td>
</tr>
<tr>
<td>SEVERE</td>
<td>20-34</td>
</tr>
<tr>
<td>MODERATE</td>
<td>35-49</td>
</tr>
<tr>
<td>MILD</td>
<td>50-69</td>
</tr>
</tbody>
</table>

[II] Impairment of Adaptive/Social Functioning:

The concept of Adaptive/Social Functioning is very broad and relates to a persons performance in coping on a day-to-day basis with the demands of their environment. It is therefore very much related to a person’s age and the socio-cultural expectancies associated with their environment at any given time. It is concerned with what a person does (i.e. actual behaviour/performance).
The BPS (2001) recommends the following definition for Impairment of Adaptive/Social Functioning:
- **The individual requires significant assistance to provide for their own survival (eating and drinking needs and to keep himself/herself clean, warm and clothed), and / or with their social/community adaptation (e.g. social problem solving and social reasoning).**

The degree of assistance required may vary in terms of intensity (e.g., physical or verbal prompting) and frequency (e.g., daily or less often than daily), but the required assistance should always be outside the range of that expected within the individual’s particular culture/community.

### [III] Age of Onset

For a person to be considered as having learning disabilities **significant** impairments of intellectual and adaptive/social functioning must have been acquired during the developmental period. The BPS (2001) note that consensus does seem to exist that the age of onset of criterion is below 18 years.

What is the current network of services in East Berkshire, for people with learning disabilities?

There is a community learning disabilities team, which consists of those listed below. However across the area, the expertise of team members may vary. Currently the CTPLD only provides a service to adults, i.e. those with learning disabilities aged over 18yrs. I have used the model which exists within Bracknell to illustrate a good example of the breadth of the team, and have included a case study to demonstrate how things work from a patient/carer perspective:

<table>
<thead>
<tr>
<th>Team Management</th>
<th>Occupational Therapist</th>
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</thead>
<tbody>
<tr>
<td>Administration &amp; Team Support</td>
<td>Physiotherapist</td>
</tr>
<tr>
<td>Community Nurses</td>
<td>Social Workers/Care Managers</td>
</tr>
<tr>
<td>Psychiatrist</td>
<td>Speech &amp; Language Therapist</td>
</tr>
<tr>
<td>Dietician</td>
<td>Psychologist</td>
</tr>
<tr>
<td>Challenging Behaviour Specialist</td>
<td>Support Workers</td>
</tr>
</tbody>
</table>

During my research of this area, I liaised with learning disabilities teams in Surrey & Hertfordshire to determine whether there was any difference in their approach. The Surrey team includes in addition to the above-a creative therapist (art/music), a chiropodist, and a GP with special interest in learning disabilities. The services form part of the Quality health forum for valuing people, and they have regular Surrey-wide health meetings-on behalf of the Surrey learning disabilities board. Interestingly there are a team of healthcare professionals currently working on producing leaflets on all aspects of end of life care, including organ donation. In Hertfordshire, there appears to be a less formal set-up, which consists of a health facilitator, health workers, learning disabilities nurses, GPs, learning disabilities & mental health commissioners.

**CASE STUDY 1: GOOD MEDICAL PRACTICE EXAMPLE: GP PRACTICE BRACKNELL:**

Mr JF, 56yrs male with Down’s syndrome, known to have severe learning disability, and on the LD register. Documented to be known to services since 1997, and having development delay whilst at school. Under SALT (speech & language therapy), for communication difficulties and problems with feeding. Known to have early cataract, and awaiting planned eye operation. Lives in care home, supported living, with 2 other residents with LD.

During annual health check by GP, in October 2007, noted to have new onset constipation and unexplained weight loss, but patient not allowing abdominal examination. Attempt to perform blood tests unsuccessful, as patient refused! January 2008, carers noted new onset feeding difficulties & bleeding from gums. Decision made to refer to CTPLD (community team for people with learning disability) in February 2008, for assessment of patient’s capacity to consent to blood test, for dental review & planned eye operation. Review by psychiatry in June 2008, in agreement with medical decision, that patient needs urgent investigation of these symptoms. Multidisciplinary meeting held in June 2008, involving CTPLD, community nurse, dietician, SALT, care home manager and senior support worker, in line with making an urgent decision re: capacity to consent to above procedures. Several team members had noted a change in the patient:

- **BEHAVIOUR:** displaying signs of **distress when eating**, noted to have **oral bleeding**. Going to bed earlier than normal, and spending **more time in his own room**. Patient refusing examination & tests!
COMMUNICATION ABILITY: known severe learning disability as displaying difficulty understanding instructions of more than one word, needing to use objects and multiple repetitions of instructions to support communication with patient. Inconsistency noted in his ability to follow simple instructions.

COMPREHENSION: displaying no awareness of any outcomes or implications of refusing treatment, according to care home manager.

All members present concluded that this patient lacks capacity to consent, and in view of the new symptoms requires urgent investigation & treatment- refer to GP.

- October 2008, patient now noted to left facial swelling, and treated with antibiotics for suspected dental abscess.
- November 2008, referred for dental review, but unable to perform examination.
- January 2009, Annual Health Check - follow up of MDT decision, no new problems noted.
- July 2009, bloods all normal.
- December 2009, GP notes patient has papilloma on tongue (growth on tongue), and urgent referral made to oral surgery! Now under their care for mouth symptoms.....

80% those with Down’s syndrome thought to suffer with dental problems⁴; continence one of nine key health issues affecting those with learning disabilities¹, 70% suffer from constipation – often due to lack of fluid or dietary fibre, poor mobility & drug side effects⁴.

All patients known to CTPLD in Bracknell have a personalised health action plan in an attempt to them having greater choice & control over their lives (Ambition 6 & 8-10). During my time in Thames Hospicecare, I came across a patient that had been handled very well by a colleague. This was a female patient aged 68yrs, with oesophageal cancer and known moderate learning disabilities, living in a care home. Over the course of six weeks she was offered the opportunity to visit the hospice, in order to become familiar with the environment & staff, as she was approaching the terminal stage of her condition. She did have a health action plan, which the carer had been helping to prepare, and which stated her choice of preferred place of death to be in the hospice and included a decision for DNAR (do not attempt resuscitation), along with patient choice of funeral arrangements, etc. She was eventually admitted for end of life care to the hospice, as carers had noted change in her behaviour, i.e. patient mobility deteriorated, bedbound, no longer wishing to get up even to smoke cigarettes over the last week. She died peacefully within hours of her admission to the hospice!

Where are the gaps?....

One of the difficulties in the needs assessment was the distinct lack of data, across East Berkshire. The only area with a database is Bracknell! Maidenhead have a limited spreadsheet-but they admit this is not comprehensive! In view of this, it is not possible to comment on the process of how well people with learning disabilities, currently access end of life care in East Berkshire. Specific information that is lacking includes main diagnoses/ statistics on cause of death; finding those with learning disabilities and a diagnosis of cancer was next to impossible! Bracknell appears to be the exception, as they have a good database & GPs work closely with CTPLD to ensure appropriate access of people with LD to all areas of NHS. Case examples enabled me to comment on how effective the service is on an individual level, but I am unable to predict population need at the present or predict future needs!!

Bracknell: 380 total LD + 76 people out of county (51% of total population in East Berks)
Total Deaths =9
THE LEADERSHIP FELLOW EXPERIENCE: ‘Shaping Tomorrow’s Leaders Today’

The whole essence of this programme has, for me, been a transformation in my perspective on the way I view the NHS and my work within it! It has made me realize the impact & influence we can all have on the environment and people around us, especially working within the NHS today. Change is the only constant, within the NHS, and contributing towards the process of positive changes and helping to maintain good medical practice, is a quality outcome/ improvement in itself! The tutorial sessions have helped me to learn about factors which contribute towards making policy, the whole patient experience and a whole lot more about me. Particular highlights of the programme have included learning about the concepts of emotional intelligence, how the use of neuro-linguistic programming can help boost and transform negative thoughts to positive experiences, and of-course not forgetting the knowledge of one’s personality traits via Henry V’s model!

The project to date, has made me realize the potential of my own leadership skills, how to overcome some of the barriers to change, and the importance of establishing good relationships with colleagues at all levels. It has also made me realize the challenges which lie ahead with providing healthcare and addressing health inequalities in this particular patient group! I hope that having gone through this process, I can endeavour to lead by example.

RECOMMENDATIONS:

Listed below are the main recommendations, following on from my project findings:

- Need for a comprehensive central database/ register of people with LD, including diagnosis of chronic disease and cancer (Ambition 12)
- Future audit/ survey to evaluate how effective the current system is
- Collect data from annual health checks (in place since 2007), useful to predict future commissioning of services re: END OF LIFE CARE in those with learning disabilities
- Ensure high standard of care across South Central Strategic Health Authority (Commitment 5 & 6)

March 2009: Ombudsmen recommend urgent review of:

a) Effectiveness of the systems they have in place to understand and plan to meet the full range of needs of people with learning disabilities in their areas

b) Capacity & Capability of the services they provide/ commission for their local populations to meet the additional & often complex needs of people with learning disabilities – data collection from Annual Health Checks will be very useful in this.

THE NEXT STEPS/ PROGRESS SO FAR:

- Create future leadership fellow project to take this work forward, working with Dr Matthew Stephenson, LD Consultant Ridgeway Partnership- to take some of my work forward
- The key to future change is having data–who are the people with learning disabilities? Who can create & maintain a central database for south central SHA? Networking with other colleagues in other areas/ strategic health authorities to share findings and learn from how other areas are addressing key priorities re: learning disabilities/ end of life care.
- VTS ST1/ST2 learning disability study day in June 2010
- Presentations to ST3 and trainers in oxford deanery re: leadership fellow scheme
- Publish article re: patient experience in end of life care;
APPENDIX A- More info on LD

Psychometric assessment using WAIS-III UK  This test is based on a normal distribution of general intelligence where significant impairment of intellectual functioning has, by convention, become defined as a performance more than 2 standard deviations below the population mean. The mean is 100 and the standard deviation is 15. More than 2 standard deviations below the mean thus correspond to an intelligence quotient (IQ) of 69 or less.  

“Learning Difficulty, rather than learning disability, if:

1. Problems with reading, writing or numeracy only.
2. Emotional difficulties that may sufficiently have disrupted schooling, influencing achievement.
3. Conditions like Attention Deficit Hyperactivity Disorder (A.D.H.D.) or hyperactive disorder.
4. Asperger’s syndrome and some individuals with Autism. However, some people with Autism can also have a learning disability as well as a learning difficulty.

REFERENCES

1. Valuing people 2001 Department of Health (DoH)
2. End of Life Care Strategy -Dept of Health 2008
3. BILD (British institute LEARNING DISABILITIES) study commissioned by DoH
4. Information from recent presentation to GPs by Jane Knowles, Community Lead CTPLD Bracknell- information included with her consent.
5. Lord Darzi next stage review
6. Sir Roger Bannister Summit (organised by the King’s Fund Nov ‘09- 10 critical actions to help the successful implementation of the strategy; improving quality of care to patients EOLC:

CHALLENGE IS RISING NUMBER OF DEATHS & PRESSURE ON FUNDING:

i) Demonstrate the case for change with evidence- identify examples of best practice form local, national, international research; cost effectiveness & evaluation of new models of care

ii) Commission for outcome- DoH identify available levels of funds for different aspects EOLC to allow focus on commissioning quality services that achieve defined outcomes within available funding.

iii) Define the local model of care- establish right model of care to meet identified outcomes for their population (eg consider needs LD/ specialized groups)

iv) Identify care pathways and triggers for care- determine prognostic indicators to help identify those nearing end of life care, traffic light system, end of life care registers; GP role important

v) Ensure timely access to care 24hrs/day

vi) Develop flexible solutions to meet a whole range of needs which include, but are not exclusively, health care solutions.

vii) Improve care in all settings

viii) Improve workforce skills & confidence

ix) Ensure manageable & meaningful local measurement- e.g measure of outcome rather than the process i.e. 24hr access, end of life care pan in place= could be in QoF

x) Completing the loop: has the national strategy delivered for patients & carers? - Surveys of bereaved relatives, the National Voices survey, the national Care of the Dying Audit +

7. Strategic Direction NHS Operating Framework