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living with dignity

Collaborative Working: Palliative Care and Learning Disability Services

The journey to the Linda McEnhill Award - and beyond!

For the PCPLD Network Conference 10th May 2010

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Saint Francis Hospice on behalf of colleagues from our local
LD and palliative care patch

The beginning of our journey

Two memorable patients:



1. A 48 year old man with advanced bowel cancer and also moderate LD

- Diagnosed late: residential home did not pick up that his behaviour changed because he was poorly
- Now back at home with mum and dad after many years
- Very symptomatic: pain, vomiting, fatigued
- His GP, who knows us well, sought our help
- Patient wondering what's wrong: No-one telling
- Staff finding him hard to read/unpredictable. Staff frightened of him.
- LD nurse a key support to mum, dad, patient, and us.



2. An elderly lady with advanced renal cell cancer - and also severe LD, living in a residential care home for many years

- Referred by hospital to hospice for terminal care.
- 'Couldn't go back to care home' as needs 'too great'
- Very poorly on admission
- Matron concerned to see her so poorly – asking us 'why are you not sending her back to hospital for emergency care?'
- Her advocacy for patient very strong-a heavy duty
- We didn't think to ask LD nurse for help –for her, for her friends, for the matron/staff, for us.



For both, living with illness and dying fell short of ideal.



We were unhappy



Couldn't we do better?



Next - an inspirational workshop!



- **In early 2007**
- **Run by Help the Hospices**
- **'Widening Access to Palliative Care'.**
- **A participative forum attended by senior representatives from a range of palliative care services**
- **Speakers spoke about a range of people who had a tendency to miss out on our care services**
- **Linda McEnhill spoke of difficulties in access for adults with LD**
- **Meaningful for us**

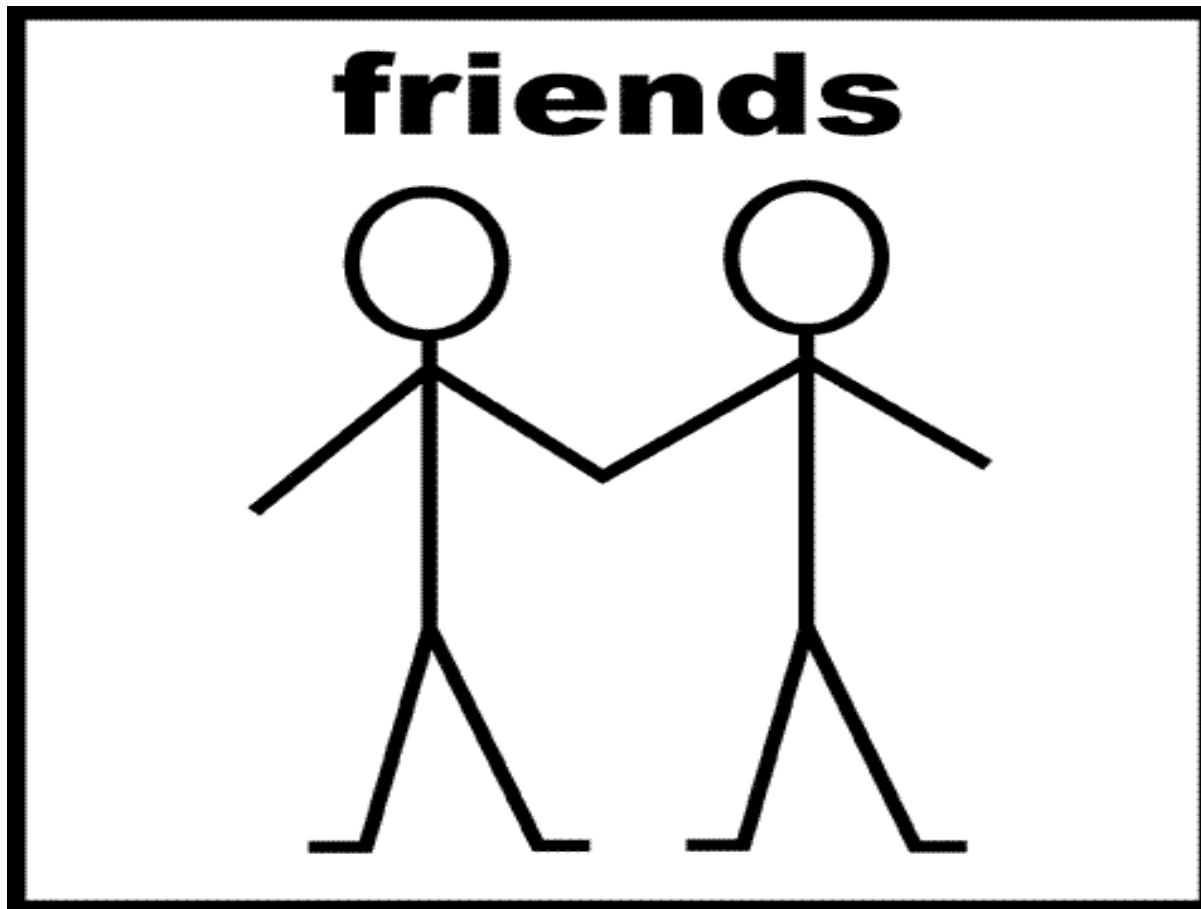


Our task



- To find local people who knew and worked with adults with Learning Disability
- To meet with them, alongside colleagues from the local range of specialist palliative care services...
- ...and representatives from the 'front line' of generic palliative care services
- To discuss the care journey from pre-diagnosis through to death and beyond...
- ... to better understand challenges, and obstacles to best care





We started with people we knew..
.. which was a very good place to start
Patient 1 and Patient 2's LD key worker.



Expanded to include:

- **Pt 1's GP and DN**
- **Additional reps from LD services to ensure all 4 local PCTs represented**
- **A rep for vulnerable adults from our 2 local hospitals**
- **Mencap/other charitable support bodies**
- **Reps from residential/nursing care homes supporting adults with LD**
- **1 other GP/DN lead**
- **Reps from all local specialist palliative care services**





REALLY ENLIGHTENING!!

- **Positives:**

- a passionate shared concern to bring best care to those who need it.

- **Surprises:**

- a huge gap in our understanding of support services and supportive material for people with LD
- a huge gap in their understanding of health, social and specialist palliative care services available to support through difficult times.





From discussion to action: Formation of a 'working group' for tasks:

1. Need to revise our Referral for Palliative Care Services form:

- **Vulnerabilities**
- Some people may be particularly vulnerable – please circle if any of these vulnerabilities apply or give details of any other.

Learning Disability

Dementia

Cognitive Impairment

Significant Mental Health Background

Other (please state)

- Is there a key worker involved? Please give the name of the key worker and the organisation involved.....



2.and to develop a special processing of referrals for people with LD

- We developed a Fast Track Pathway towards early face to face contact with the patient and their key worker
- The pathway stressed the need for strong and continuing engagement with and support of the patient, their key worker and key family



3. Need to increase confidence for us all, to manage the unfamiliar together

- A teaching programme to launch the pathway
- Provision of an informative resource for staff
- Tools to support staff though new territory
..... to communicate effectively

This proved necessary, and valuable, both in the Specialist Palliative Care Setting AND in the Learning Disability setting





The big, brave launch:

**Our Annual Conference on 6th Nov 2008:
'Learning Disability: ensuring excellence
and empowerment in end of life care'**

Key themes:

- the personal experience
- the patient experience .. carer memories
- A hospital (professional) scenario
- Keynote speakers: Linda McEnhill and
Irene Tuffney-Wijne



Here we are, talking about all sorts of things!



Key gains:



- **Who we targeted to come/who came**
- **Realisation of peoples' vulnerabilities**
- **A motivating focus for our working group**
- **New members**
- **The formation of internal champions to share the practical load**





Keeping us on our toes: The value of annual reflection

- **Review of 17 months of the pathway:**
 - **Of 1684 referrals received, 7 people with LD**
 - Only 3 forms/notes identified a key worker
 - Referrers: **GP/DN (3), oncology CNS(1) or Hospital Pall Care CNS (2), LD key worker (1)**
 - 6 patients had cancer **(3 at early stage)**
 - The chief 'ask' was for carer support **especially re. the future**
 - **Pain control a worry for 5/7**
 - **6 were in care home accomodation – only 2 with regular family contact**



- **Only once was contact made within 1 working day of receipt of referral**
- **No one got an early (<1 week) Saint Francis Hospice community nurse visit.**
- **All patients concerned were eventually visited by our CNS, or nurse from our Hospice at Home Team – which helped ENORMOUSLY!**

Action: sharing of results with our clinical teams to ensure understanding of:



1. the key place of carers in their care
2. carers' vulnerabilities
3. carers' common concerns
4. what 'home' is for many adults with LD
5. how very valued early support is...



6. ... and best given face-to-face
... fine to dip in and out of face to face contact, but when there are worries - it is so helpful
7. how easy it is to be really helpful
8. the value of good documentation!

What are we doing now?



1. 'Vulnerable Adults lead at local hospitals is now in our group
2. New mandatory annual training in LD for all hospital staff
3. Our latest annual audit (to end Mar '10):
 - 5 patients referred with LD
 - 100% key worker identification
 - 3 contacted within 1 day
 - 2 contacted within 2 days
 - 3 early visits made.
 - 2 died too quickly for 'early' visit.





Reflections

- Collaborative working takes time and energy but worth it:
- HAS sustained because committed people at the group's heart
- Conference gave us a focus, and our work a profile
 - Opportunity to look constructively at different ways of doing things
 - Brought more commitment – esp from hospital and care homes
- Referral form has raised the profile of the vulnerable
 - allowing us to reflect and learn
 - Reminding staff here of key external relationships
 - we do see more people with LD now
- Positive feedback by care givers
 - All our patients in this last 2 ½ years have stayed at home, with H at H support as needed
 - LD key workers able to 'flag' potential value of/reassure about hospice support services and 'flag' palliative care services in hospital
 - Community team much more confident with this client group



.. And in the near future

- **Study Day: Learning Disabilities and life limiting illness: a continuing journey 17.2.11**

Target Audience:

- Health and Social Care Professionals involved in supporting adults with learning disability
 - Care home staff supporting people with LD
 - Professionals delivering EOL Care
 - Adults with LD, their families and friends
- **Discussion with commissioners for better provision of hands-on-care to allow vulnerable people to stay with friends and 'family'-at home**



**Many thanks to you all for your kind
invitation**

**And for your support of our initiatives in
these last 3 years**