THE NATIONAL COUNCIL FOR PALLIATIVE CARE

#dyingwithdementia
#dementiachallenge

7th Annual Conference on Dementia & End of Life

Rising to the Prime Minister's Dementia Challenge

Tuesday 4th December
15 Hatfields, London

Are you Tweeting today?

If so, please use **#dyingwithdementia & #dementiachallenge**

(if you have space for both)

Follow us for live tweets...

- **@DyingMatters**
- **@SimonSimply** - NCPC Director of Policy & Parliamentary Affairs
- **@AliceFuller** – NCPC Policy & Parliamentary Affairs Lead

Improving Health and Care: Rising to the Prime Minister's Dementia Challenge

directors of adass
adult social services

The PM’s Challenge

- Dementia friendly communities
- Dementia research
- Improving health and care

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Improving Health and Care

- Diagnosis
- Quality Care
- Innovation
- Care Compact
- Information

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Dementia Care and Support Compact

- I am respected as an individual.
- I get the care and support which enables me to live well with my dementia.
- Those around me and looking after me are well supported and understand how to maximise my independence.
- I am treated with dignity and respect.
- I know what I can do to help myself and who else can help me.
- I can enjoy life.
- I feel part of a community and I am inspired to participate in community life.
- I am confident that my end-of-life wishes will be respected. I can expect a good death.

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15 Point Plan
1-5

- Improve diagnosis rates
- Better care in all settings
- Support for carers and families
- Information – “ No wrong door”
- Commissioning an enlightened workforce

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15 Point Plan
6-10

- Reduce use of anti –psychotic drugs
- Improve people's living environment
- Improve access to enablement and intermediate care
- A dignified death
- Cultural and implementation challenge

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15 Point Plan
10-15

- Describing what excellent care looks like
- Develop local performance management systems
- Build understanding and capacity in CCGs
- Develop clear view on integrated working
- Communication and engagement plan

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Driving Progress

- Champion Groups
- Sub Groups
- Wider networks
- Dementia Programme Board

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National action

- Support to improve diagnosis rates
- Work with NCPC to raise awareness re end of life planning and choices
- Prize funds to promote innovation
- Skills for care fund for training
- Sign up to care and support compact
- Raising the profile, promoting action

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Local delivery

- Working with schools
- Support from Police and Fire Services
- Making memories
- Dementia training and accreditation
- Dementia champions
- Dementia cafes
- Training adn support for carers

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Launch of new NCPC & Dying Matters DVD for GPs to support people with dementia

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What's the issue?

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Dying Matters 'Let's talk about it'

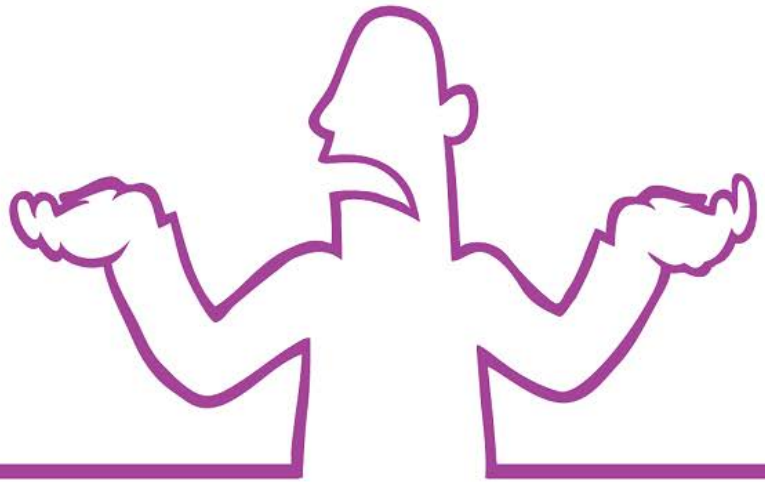
No evidence that people with dementia experience less pain and distress

+

Good evidence that people with advanced dementia less able to verbally communicate pain and distress

+

Good evidence that pain and distress is under-detected and undertreated



What can be done?

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Dying Matters 'Let's talk about it'

- No simple, easy-to-read brief guidance available for all audiences
- NCPC were asked by Prime Minister, as part of his Challenge on Dementia, to produce short guidance, being launched today
- Produced with help from the Dementia Group, consisted of a range of professionals and academics

www.ncpc.org.uk

www.dyingmatters.org

What it includes

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Dying Matters

'Let's talk about it

Unusual behaviour may be a sign of pain or distress

Knowing whether someone is in pain or distress

What can you do if someone is in pain?

Some examples of things that might be causing pain or distress

The bottom line:

Distress or 'challenging behaviour' is not "just part and parcel" of having dementia things can be done

www.ncpc.org.uk

www.dyingmatters.org

Practical tips

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Dying Matters 'Let's talk about it'

- Ask the person what the matter is
- Listen to them
- Observe their behaviour and what's going on
- Act on what you've seen and heard

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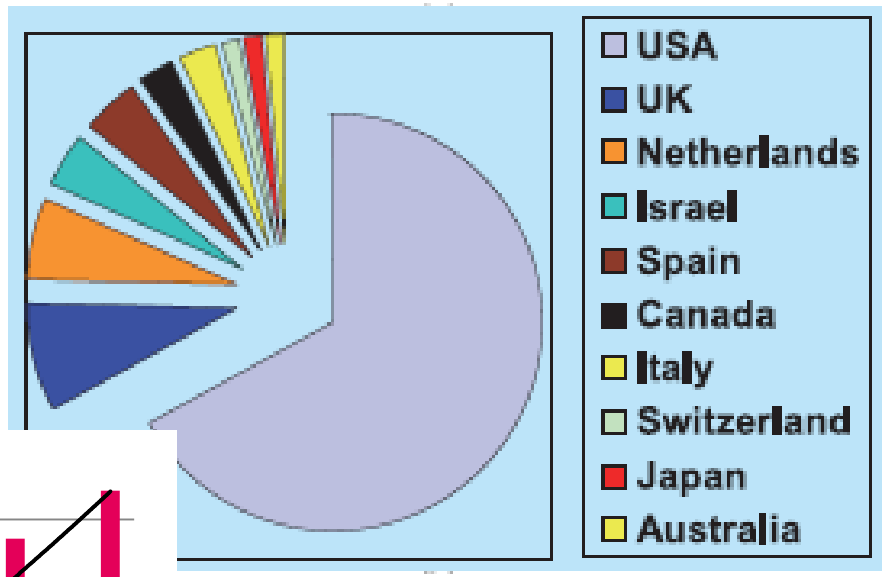
Research in end of life care: rising to the PM's challenge

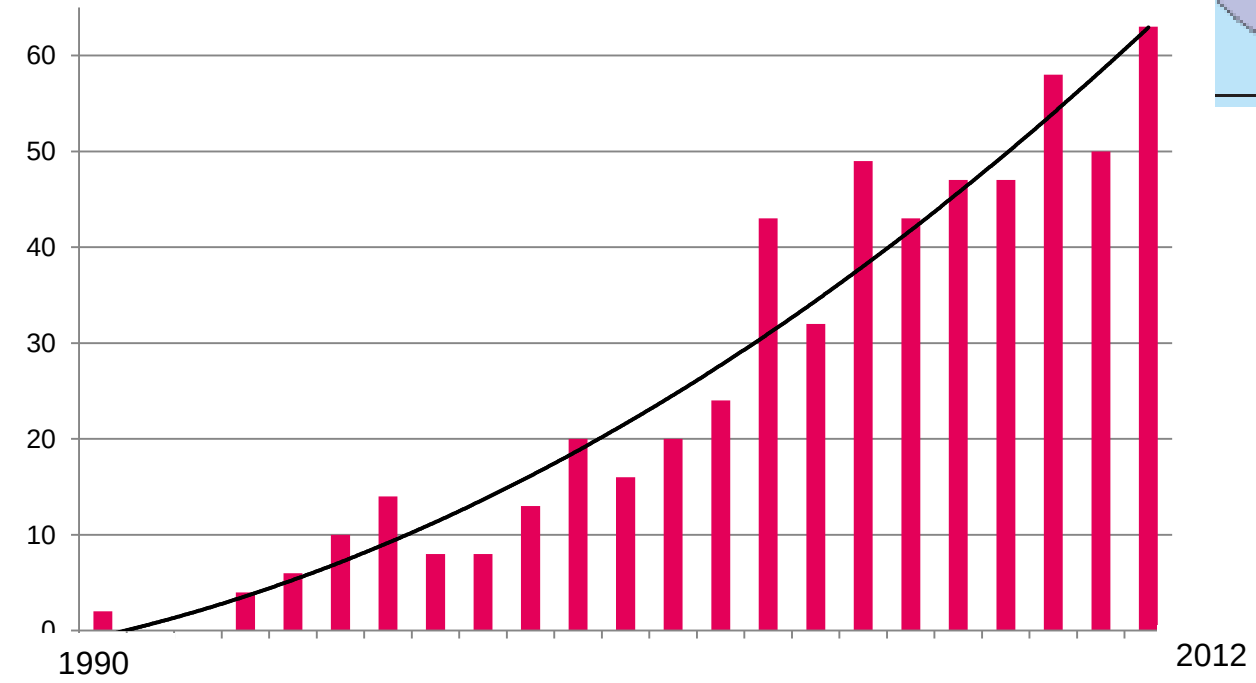
Dr Liz Sampson

Senior Clinical Lecturer, Marie Curie Palliative Care Research Unit

Mental Health Sciences Research Unit, University College London

How much are we doing ?





The PM's challenge- research

- Funding more high-quality research into care, cause and cure
- Social science research focused on living well with dementia and on the delivery of dementia care services.
- £13m funding for social science research on dementia (NIHR/ESRC)
- Participation in high-quality research offering people the opportunity to participate in research will be one of the conditions of accreditation for memory services.

What do we know so far…?

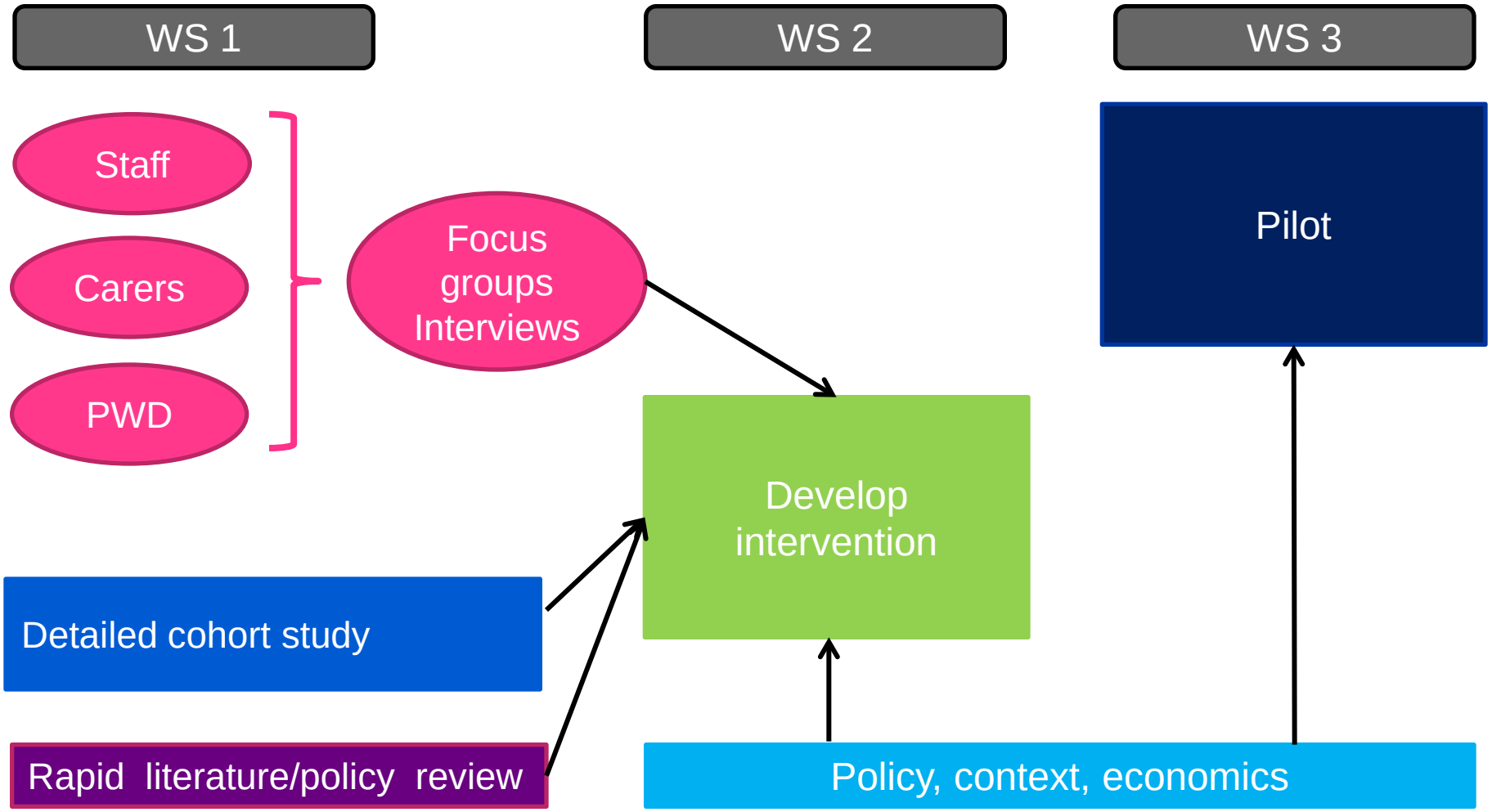
- Individual symptoms
  - Pain
  - Artificial hydration and nutrition
- Population statistics (NEOLCIN)
  - Cause of death
  - Place of death
- Problems
  - Access
  - Staff training

What do we need to know?

- Take a holistic approach to establishing the needs of people who are dying with dementia
  - Quality of life
  - Behavioural and Psychological symptoms
  - Comfort
  - Pain and distress
  - Spiritual and existential needs
- Informal carer, friends and families

How to implement change to improve care ?

The CoMPASs:IOn Programme Grant



Other key UK research

- Newcastle University- Professor Louise Robinson
  - Advance care planning
  - SEED Programme
- University of Hertfordshire- Professor Claire Goodman
  - Care homes and multi-morbidity
  - EVIDEM-EOL
- St Christopher's Hospice-Dr Jo Hockley
  - Implementation of GSF
  - Namaste care
- Lancaster University-Dr Kathryn Froggatt
  - Dying with dementia in care homes
- Nottingham University- Dr Kristian Pollock
  - Dying with dementia in acute medical wards

What is holding us back ?

- “Ethics”
- “Governance”
- Bureaucracy
- What is “better care”
  - Outcomes
  - Quality
  - Economics
  - For who ?

What is moving us forward ?

- Demographics
- Recession
- Policy
  - NHS commissioning board
- 3rd sector support
- Funding
- Research network support
  - DeNDRoN
  - **EnRICH**

Goodwill

In conclusion

- Huge increase in end of life care research in dementia
- UK is a *potential* leader in this developing field
- Research needs to answer questions of holistic care for people with dementia and their families and friends
- Need to consider service delivery, economics, outcomes
- Research has to combine mixed methods in a wide range of settings
- There is a huge appetite to participate but we are being held back

Why this matters

Len Sampson 1929-2012

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Panel Debate

Thank you to members of Uniting Carers, Dementia UK for participating in today's event

Please visit Dr Jennifer Bute's website for more information:

www.gloriousopportunity.org

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Seminar B: Care planning & decision-making for people with advanced dementia

Dr Fiona Boyd, Consultant in Eldercare & Dementia Clinical Lead, Royal Cornwall Hospital, NHS Trust Cornwall

Supporting Decision Making in Advanced Dementia with Medical Care Planning - making the Right Decision at the Right Time.

Dr Fiona Boyd

Consultant In Eldercare
Royal Cornwall Hospital NHS Trust
In alliance with Dementia Partnership Cornwall

Advanced Medical Care Planning

- Background – to developing the ‘model’
- The Cornwall Model
- Results so far
- Future development?

NHS Cornwall and Isles of Scilly & Royal Cornwall Hospitals Trust Nursing Care Home Admissions Audit 2009

AIMS To identify the numbers of patients admitted from nursing homes with a view to:

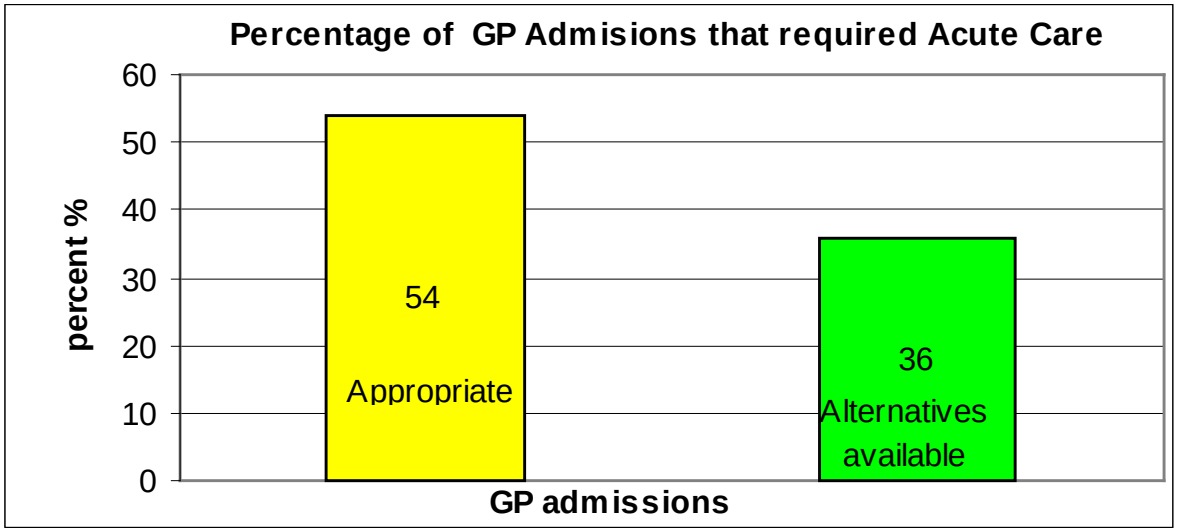
1. Identifying the appropriateness of admission i.e. those requiring acute care (whether there is an alternative to admission to hospital).
2. How to prevent unnecessary admission
3. Facilitating the patient illness journey in the best setting for the individual.
4. Considering the potential cost implications of inappropriate acute admissions of people with dementia

KEY AREAS FOR SCRUTINY INCLUDED

1. Source of referral i.e. 999 or via GP
2. Involvement of GP prior to admission
3. Hour of admission
4. Reason for admission / Diagnoses
5. Length of stay
6. Place of discharge (final outcome)
7. Alternative treatment options
8. Cost implications around end of life care and admissions

GP INVOLVEMENT

54% required acute care.



REASON FOR ADMISSION

Medical Conditions	Number of patients (n221)	Percentage %
Infection LRTI UTI Other(ulcers/gangrene, meningitis)	**39** 23 9 7	**17.6**
Falls Fracture No fracture	**30** 16 14	**13.6**
Cardiac (MI,ACS,AF,CCF)	**16**	**7.3**
Stroke	**14**	**6.3**
Breathlessness and fatigue	**11**	**5.2**

OUTCOMES AND ALTERNATIVE OPTIONS

Alternative treatment option	Number of patients
Antibiotics	25
Intravenous fluids	4
Bowel /bladder care	4
Pain management	7
Stroke/TIA (in severe dementia) –*no intervention*	4
Falls prevention	10
End of Life care plan	67
Step up –place direct from community	9
Total	**130 (59%)**

PALLIATIVE ADMISSIONS

In total study (n221)

71 were admitted for end of life care (palliative)

Died in Hospital **58**

(**81 %** of EoL subgroup)

END OF LIFE COSTING

(based of non elective national tariff)

- Total £143,485 (over 11 months) (Mean £12,4504)

- Mean cost per person admitted for EoL care £1486.24 (**£2020.92** +cc).

The above is based on PbR Tariff for 2010-11 – these figures were used to help quantify costing in real time.

WHAT IS ALREADY KNOWN?

Admissions in the last 6 months of life
average cost

£5651 - £9955

Haringey 2009

WHAT IS ALREADY KNOWN?

Factors related to hospitalization cost each acute hospital

£6 million a year

National Audit Office

WHAT WAS ALREADY HAPPENING?

- The Gold Standards Framework for EoL care
- Nursing Homes having training (GSF and for dementia care)
- Supporting Advanced Care Planning as pare of GSF
- **What about Capacity**?? – There was a ‘gap’

WHAT WAS NOT HAPPENING?

Patients without capacity (for EoL decisions) were not being supported or facilitated to make Advanced Medical Care Plans

…..SO WE DECIDED TO….

Develop a toolkit and to facilitate the legal framework of care planning for those who lacked capacity for end of life decisions!!

THE CORNWALL MODEL

1. Develop and provide GP's with a toolkit to facilitate and support the legal framework of advanced planning
2. Provide education and awareness to Primary care teams around practicalities and legalities.
3. Raise awareness of the role of medical care plans and patients needs.

THE CORNWALL MODEL

Multi-agency co operation and integration

- Provide seamless care
- Improve end of life care for those with advanced dementia
- First stage was to identify Stakeholders

THE CORNWALL MODEL
The Stakeholders

- ✓ Out of hours GP
- ✓ Emergency services
- ✓ Emergency Departments
- ✓ District Nurses
- ✓ Community Mental Health Teams
- ✓ Locality GP Leads
- ✓ Social Care
- ✓ Coroner
- ✓ Private providers
- ✓ Voluntary Sector

OBJECTIVES

- ✓ Identify the major barriers for people with dementia in accessing good quality end of life care.
- ✓ Improve End of Life care
- ✓ Reduce deaths in acute hospital
- ✓ Reduce hospital admissions
- ✓ Implement cost effective ways of enabling sustainable improvements

OBJECTIVES

- ✓ Improve communication between all agencies
- ✓ Provide bespoke training to all agencies and families/carers
- ✓ Ensure family involvement and satisfaction of care
- ✓ Anticipatory care planning
- ✓ Break down organizational barriers; normalize dementia, allowing access to specialist services

THE CORNWALL MODEL

Meeting with General Practitioners

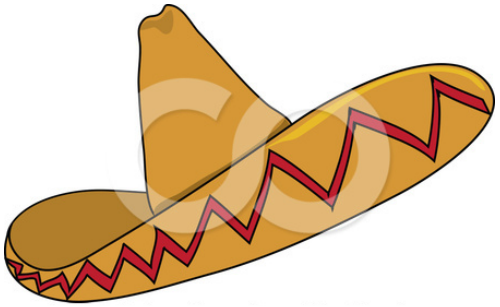
Meeting with Nursing Home staff

Organize any training as necessary

THE CORNWALL MODEL

Invite carers and all staff to a meeting

Invite discussion about End of Life



CORNWALL COUNCIL

Alzheimer's Society Leading the fight against dementia

NHS Cornwall and Isles of Scilly

Preparing for End Stage Dementia

Information for people with dementia, their family and carers

A guide to planning ahead for relatives and carers on behalf of person with end stage dementia

A patient information leaflet produced by

NHS Cornwall & Isles of Scilly & Alzheimer's Society

THE CORNWALL MODEL

Toolkit operational – ‘best interest’ framework and checklist.

Invite the relatives/carers (interested parties) to a Best Interest meeting with the care home staff and representative from primary care.

THE BEST INTEREST MEETING

- Role of Cardiopulmonary Resuscitation
- Preferred place of death
- Admission to Hospital
- Other active interventions (ie role for further active treatments such as antibiotics, hydration, medication; LCP)

¶ In the opinion of those consulted, if the person's condition changes, the most appropriate place for them to be cared for in their best interest would be:¶ ¤
¶ Sunshine care home¶ ¤
¶ Are there any additional thoughts that should be taken into account by others?·¶ ·¤
¶ ¶ These reflect Mrs Bloggs past likes and things that have a meaning, staff together with her family will ensure the following is in place during the end stages of Mrs Bloggs Life.¶ ¶ Family will be contacted and remain with Mrs Bloggs¶ Sounds of the sea and Cornish male voice choirs (tapes provided)¶ Pictures of her husband next to her¶ Her favourite smell is lavender.¶ Fresh scented flowers (·family will provide)¶ ¶ ¶ ¤

THE CORNWALL MODEL

- Signed by legal decision maker – GP
- Supporting evidence for the Allow Natural Death or Expected Death documentation
- - “red form”
- Information shared with on-call/ emergency services and families.

RESULTS

6 Nursing Homes ; 4 Residential Homes

They held BIM to discuss end of life decisions and completed the paperwork – returned to GP to review and authorise before sharing with other relevant agencies.

RESULTS

1. 200 Best interest forms completed
    - 1 Refused – Nominated GP
    - 1 Refused to engage
2. Any admissions were records
3. Place of death
4. Qualitative data for relatives and care homes

RESULTS

49 Deaths

All of them in the place of residence

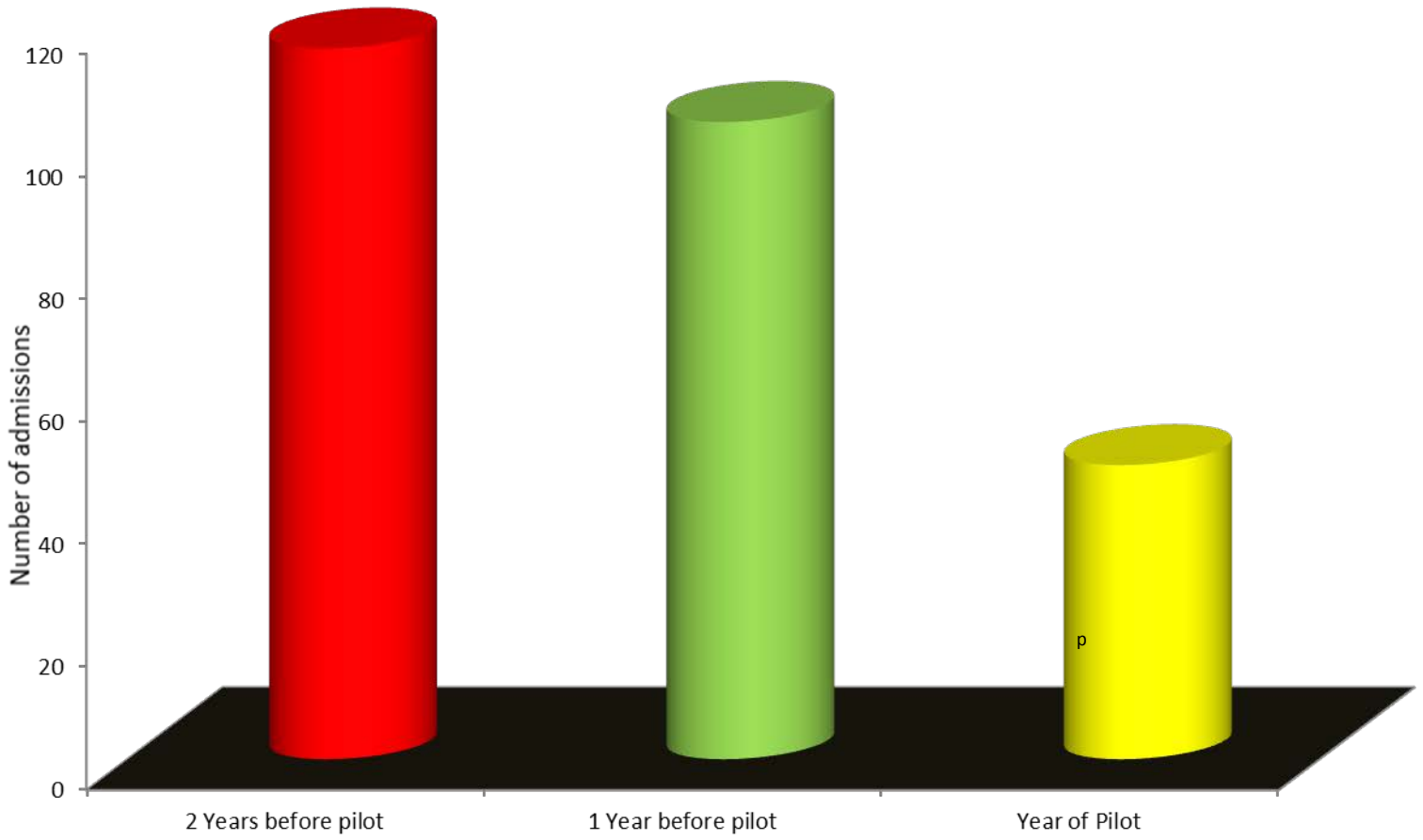
45 had Liverpool Care Pathway

NO inappropriate admissions so far

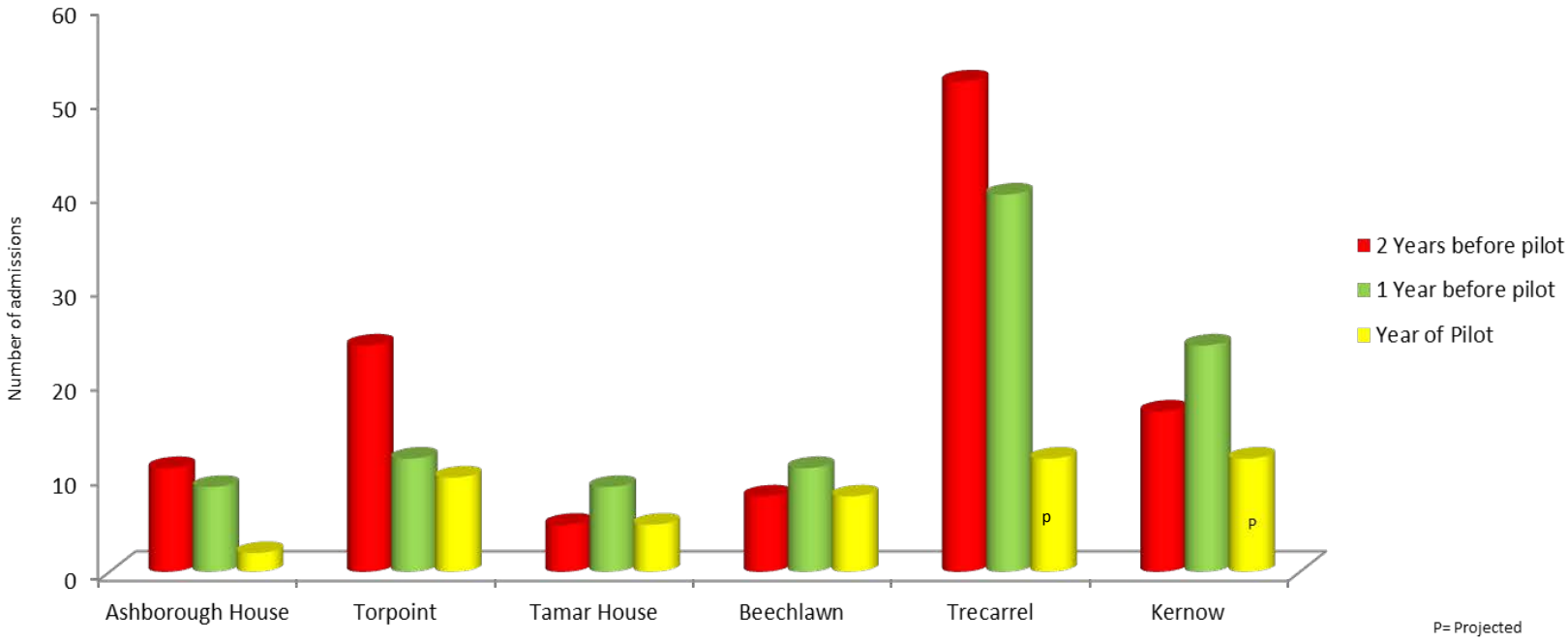
8 Appropriate admissions

50% reduction in admissions

Bar chart of total hospital admissions from homes in pilot and preceding 2 years



Bar chart to show break down of number of hospital admissions from homes in the pilot for two years before pilot and year of pilot



QUALITATIVE EVIDENCE

Excellent attendance from relatives for the meetings

Trecarrel – 19th October 2011 – 45 Attendees

St Annes – 15th February 2012 – 18 Attendees

Eventide – 22nd February 2012 – 22 Attendees

QUALITATIVE EVIDENCE

MW – Manager at Trecarrel Care home
"This pathway has enabled the patients to have a voice; difficult decisions are clearly documented and have facilitated the communication between all parties. The relatives appear to be relieved that someone is discussing these difficult issues with them"

DM – Staff Nurse at Asheborough House
"The staff and the relatives feel at ease and confident that this protects the patients. I think it is marvellous, what a great idea."

GP - "The best interest document is really useful. In situations when we would need to be having such a conversation the relevant members of the best interest discussion aren't always available and having the discussion in advance is beneficial to patients care."

QUALITATIVE EVIDENCE

Relatives

Daughter – “I’m so glad we have had a chance to discuss these issues. It was at the back of my mind and worrying me and now we have discussed it I feel so much better and confident about Mums future.”

Son –“Thank you so much for bringing this issue to the forefront of this discussion. It has highlighted so many important issues that I hadn’t considered before and am glad to have a chance to consider them.”

FINANCIAL ASPECTS

£2,020 per admission for EoL care

104 admissions reduced to 52

52 admissions ‘avoided’

52 x 2020

£105,000 saved in 10 homes

FINANCIAL ASPECTS

Project to 100 homes

Roughly half the homes in Cornwall

105,000 x 100

£1million saved?

THE FUTURE…..

Phase 2 – top 25 admitting homes

These homes had 781 admissions last year

If we avoid half of them….

£788,810 potential savings

THE FUTURE…..

Business Plan for a GP lead

QIPP

Written a package for rollout

Team of Community Liaison Nurses

Sustainable with community ownership

“You matter because you are you.

You matter to the last moment of your life, and we will do all we can, not only to help you die peacefully,

but also to live until you die." ...

Dame Cicely Saunders, founder of Hospice
(1918–2005)

THANKYOU

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Drama Session – Dementia and Me

By the Real People Theatre Company

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Alzheimer's Society | Leading the fight against dementia

Jeremy Hughes, Chief Executive, Alzheimer's Society

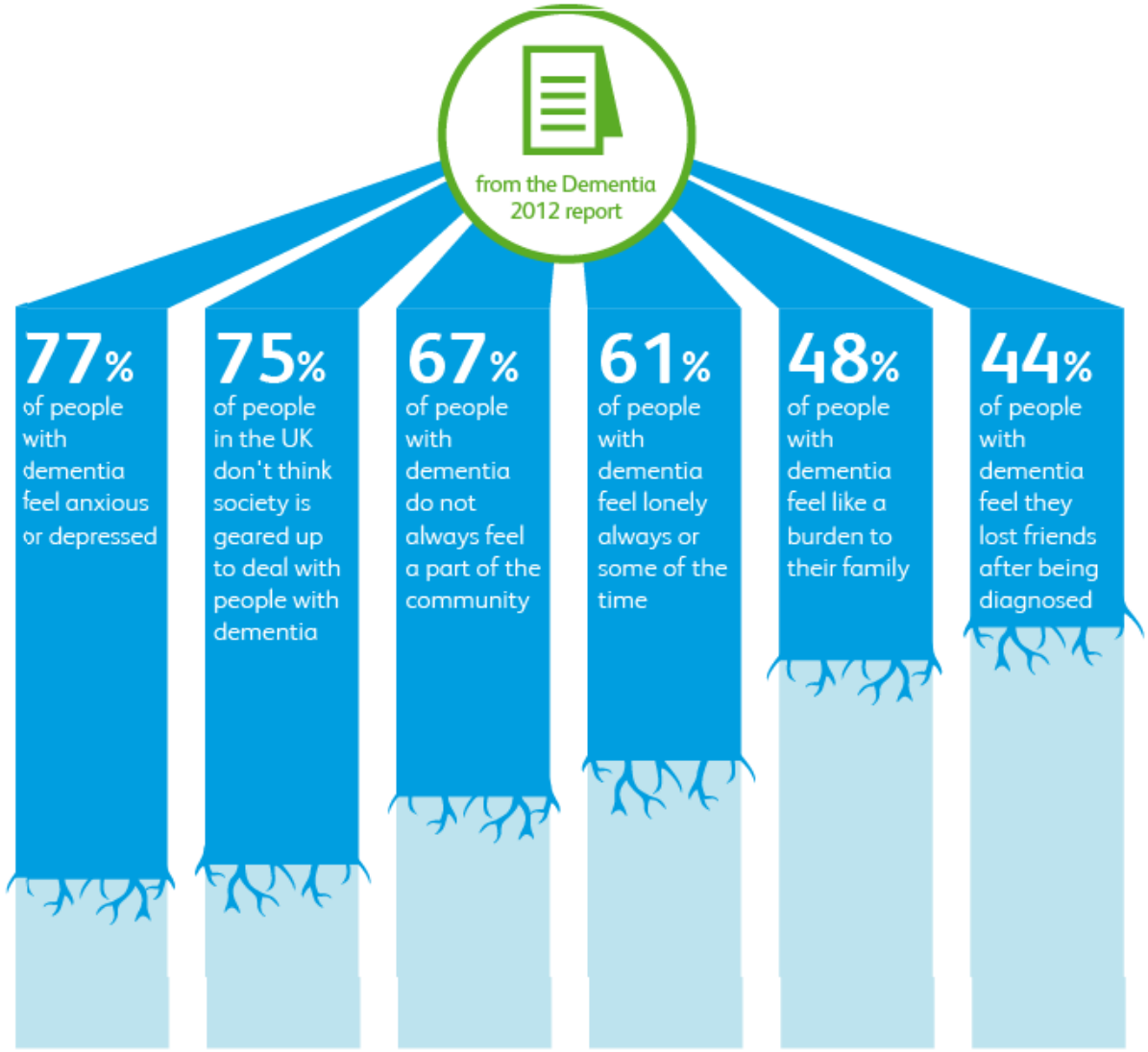
Introduction

Alzheimer's Society | Leading the fight against dementia

- Prime Ministers Challenge on Dementia
- Dementia friendly communities Champion Group
- Alzheimer's Society's role in leading development of dementia friendly communities
- Support for end of life care in hospitals
- Dementia Friends

How well are people living with dementia?

Many people with dementia and their carers are still not living well with the condition, and quality of life remains extremely varied. We all have a role to play in developing dementia friendly communities.



Alzheimer's Society | Leading the fight against dementia

Prime Minister's challenge on dementia

Key strands

Alzheimer's Society Leading the fight against dementia

Driving improvement in health and social care Under this goal there are a number of commitments such as a Care and Support Compact to improve the quality of care people receive, providing better support for carers and piloting dementia clinical networks to share expertise amongst clinicians.

Creating dementia friendly communities There is a commitment to roll out a national programme to support the development of dementia friendly communities, alongside additional targets relating to the development of local Dementia Action Alliances and high profile public awareness campaigns.

Better research Commitments on research include increasing funding opportunities and funds available for dementia research, as well as improving access to clinical trials

Alzheimer's Society | Leading the fight against dementia

Progress so far on the Challenge

- NHS institute has set out a call to action for every hospital in England to commit to becoming 'dementia friendly' by March 2013.
- Alzheimer's Society has been working with the National Council for Palliative Care to raise awareness about alternatives to hospitalisation
- There is work underway to empower professionals to support planning ahead discussions
- From the initial 10 organisations that signed up to be part of the Dementia Care and Compact, there are 42 representing 1800 care services

Dementia Friends initiative

Educate 1 million people by 2015 about dementia and what they can do to help (‘Dementia Friends’)

Enable and inspire people to become Dementia Friend Champions who will give their time and skills to improve the lives of people living with dementia

Create a social movement on dementia to improve lives for people living with dementia

Establish a national legacy of greater dementia understanding: supporting our ambition to make communities dementia friendly

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Urban and Rural Dementia Friendly Communities

Ian Sherriff University of Plymouth

Without the sense of Caring there can be “No” Sense of Community A.J Dangelo

What Promoted Plymouth Dementia Action Alliance Dementia Friendly Parishes in 2011

- Early Diagnosis of Dementia
- 70% 0f Carers and Individuals with Dementia stated “they felt isolated and not understood by their community

The Aim of Both the Rural and Urban Projects

- To develop Dementia Friendly Urban and Rural Communities, that recognises the great diversity among Individuals with dementia and their carers, promotes their inclusion in all areas of community life, respects their decisions and lifestyle choice, anticipates and responds flexibly to their dementia related needs and preferences.

Devon Parish Councils around the Yealm

- Wembury,
- Brixton,
- Yealmpton,
- Newton & Noss
- Holbeton
- The Yealm Project has: A Committee, Funding Stream for worker, Constitution Aims, Objectives, Work out puts for years 1 and 2 And a Bank Account worker in Place by August W.I N.F.U Post Offices. 30 community groups

Plymouth Dementia Action Alliance

To develop the Plymouth Dementia Action Alliance from the following groups within the city:-

Charity/Voluntary Agencies, Criminal Justice System, Emergency Services, University of Plymouth
Digital/Communications/Networks, Health Care Sector, Leisure/Tourism,
Local Authorities/Political Parties, Retail Sector, Transport, Utility Companies,
Financial Sector, Church/Faith Communities, HM Forces, the Press.

Achievement's after 12 months

- Project Worker
- Constitution
- Steering Group
- Training days
- On line Training
- 30 major organisations signed
- City centre Shops 430

Examples of Organisations Support

- The Naval Base
- Naval Families Service
- GP's
- City Council/University of Plymouth
- City Retail Sector
- Residential Care Sector
- Dartmoor Rescue
- Health and Social Care
- Blue Light Services
- Churches Together/Schools programme

Questions for today

- What barriers do people with dementia and their carers face when wanting to participate and access services in their local community?
- What changes should organisations make in order to become dementia friendly?
- What should communities do to make their area more dementia friendly? Which bodies and organisations should be responsible?
- What should be the main factors to determine whether a city, town, or village is dementia friendly?
- What examples of dementia friendly communities are already going on? What changes or initiatives have made a big difference?

Issues to Debate

- What logo will you use to Identify DFC
- What Criteria will you use for Individual organisations
- How will you monitor the process
- What constitutes a Dementia Friendly community
- Its more that a sign it's a Movement


CAUTION
THIS SIGN HAS
SHARP EDGES
DO NOT TOUCH THE EDGES OF THIS SIGN
ALSO, THE BRIDGE IS OUT AHEAD

Panel Discussion

- Any Questions

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Action Planning Session

In your groups, please discuss the points on the A3 sheets which you will find on your tables.

Fill in your Personal Action Plans (found in your delegate pack) and take these home with you.

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