Delivering Improvements by involving and supporting our carers

Dr. Chooi Lee
Emergency admissions are rising

The steepest rise in Kingston hospital is in the 90-99 year olds (up 3% 2009-13)

Patients aged 75 and over in Kingston Hospital

- Approximately 48% of patients are confused – many have dementia or suspected dementia
- Some are delirious
88 year old gentleman

- Dementia
- Cardiac disease
- Peripheral vascular disease
- Aortic aneurysm
- Infected diabetic toe
- Diabetes
- Chronic kidney disease

- Anaemia
- Pneumonia
- Falls/instability
- Fractured hip
- Delirium
- Lives alone, with social services assistance
More Important Things About Me...

Things I need to help me to communicate:

- Communication Aids
  - Glasses
  - Reading
  - Everyday
  - Dentures
  - Hearing Aids

Other things I may need help with:

- 
- 
- 

Forget Me Not

Important Things About Me

Name: ________________________

By sharing this information we hope to make your stay with us more comfortable.

Things I would like you to know about me:

I like to be called ________________________

I come from ________________________
I was brought up in ________________________
I worked as a ________________________

The people who are important to me are:

______________________________

Important things that happened in my life:

______________________________

______________________________
Kingston Hospital NHS Foundation Trust

Carer's Passport

Living our values everyday

The Trust agrees that the carrier of this card may come and go outside of visiting hours and may stay with the patient whenever required - unless there are exceptional or unforeseen circumstances.

Thank you for participating in our Carer's Passport program!
Duncan Burton
Director of Nursing

Carer's Passport Parking Pass

Valid From: ___/___/2015 To: ___/___/2015

Vehicle Registration Number:
________________________

Contact:
Dr. Choil Lee
020 8546 7711 x2791

Approved By:
Richard Evans
Transport Manager
The Triangle of Care
Carers Included: A Guide to Best Practice for Dementia Care
Carer’s Survey

1. Are you the carer of a patient with dementia who is currently in hospital? Yes / No (please circle)
2. Have you felt adequately supported during the patient’s stay in hospital? Yes / No (please circle)

* Please explain what has affected your experience positively?

* How could we improve our services to make you feel more supported?

Did you receive the “Supporting Patients With Dementia & Their Family & Friends” leaflet? Yes / No (please circle)
If yes; What department or ward you were on when you got it? ________________________
Was it useful? (add comments) ________________________
Could it be improved? ________________________

Thank you for your feedback. Please return to the ward staff. We will use your comments to help us improve services for patients with dementia.
Dementia Champions

We Want YOU!
“Mum lives in the moment. She doesn’t even know she has a broken leg.”
Quote from carer of patient with dementia, Kingston

“Life? What life. As a carer you put everything on hold.”
Quote from carer of patient with dementia, Kingston

“Two gents have just been sitting in the ward all day for a week. No one is talking to them. What about folk that have no-one coming in?”
Quote from carer of patient with dementia, Kingston
Multiple systems add layers of complexity

- 6 CCGs
- 5 social enterprises
- 7 social care
- 2 mental health trusts
- 7 CMHT for older people
- No liaison psychiatry
- Voluntary services
Supporting patients with dementia and their family and friends

First Contact: 020 8408 8170
Do you or have a current or recent diagnosis of Dementia?
Staff at First Contact will be happy to help you with information, support and advice

This leaflet contains:
- a general overview about dementia
- a description of Kingston Hospital’s Forget-Me-Not Scheme
- hospital tips for carers
- where to go for advice and support when back at home

Have you or someone you care for just been diagnosed with dementia?
How you and/or your family might be feeling at this time
If you, or someone close to you, have recently been diagnosed with dementia, you may be feeling angry, frustrated, worried, fearful, sad, embarrassed, lonely, guilty, or even relieved. Everyone is different, but all these reactions are possible at different times and they are all normal. How you feel will probably even vary from one day to the next.

Where you can find support — in hospital and at home
Kingston Hospital’s “Forget Me Not scheme” will help you whilst in hospital – make sure that you ask about how it can support you. The First Contact service can provide information and advice about support available in your area for when you go home.

The importance of diagnosing dementia
Whether you are someone with dementia, or a carer, it is very important to get an accurate diagnosis. It allows you to prepare and plan for the future. You can then find out about possible treatments, support, and advice that can make a difference.

Dementia can be diagnosed by a doctor or at a memory clinic. They should rule out any illnesses with similar symptoms to dementia, including depression or physical illnesses. An infection that can cause confusion sometimes is referred to as delirium. They may carry out a number of tests to check basic thinking processes and the ability to perform daily tasks. They may request further tests, such as a brain scan or a more in-depth assessment of memory, concentration, and thinking skills.

Adapted from the Alzheimer’s Society 2013 Factsheets

Understanding what dementia is and what causes it

What is dementia? The term ‘dementia’ describes a set of symptoms which occur when the brain is damaged by certain diseases. The most common types of dementia are Alzheimer’s disease and Vascular Dementia, but there are many others.

Some of the most obvious symptoms of dementia are:
- Memory Loss
  - Poor short term memory,
  - Inability to recall recent conversations,
  - Cannot remember what happened a few hours ago,

- Mood Changes
  - Rapid move from calm to angry,
  - Becoming withdrawn,
  - Frightened about everything and nothing,

- Communication Problems
  - Cannot find a word,
  - Loss of vocabulary,
  - Cannot spell familiar words,

Dementia is progressive, which means the symptoms will gradually get worse and will affect day to day living. How fast it progresses, and its impact, will very much depend on the individual person. The type of dementia also makes a difference.

Adapted from the Alzheimer’s Society 2013 Factsheets

Often, family and friends are more concerned about the symptoms than the person themselves.
The ‘Forget Me Not’ Scheme and how it can help you

The Forget Me Not Scheme: This ensures that hospital staff recognise individuals with a known diagnosis of dementia. Appropriate care will then be provided in the following ways:

The Forget Me Not Symbol: This is displayed beside the patient’s name to highlight their needs.

‘8 Important Things About Me’: This form summarises information about each patient, such as their likes and dislikes. A member of staff fills in this form with the patient and their carer or relative. With their permission, it is made clearly visible so staff can provide effective care adapted to the patient’s unique needs on every occasion.
(Tip – Check the form is with the patient throughout their stay to ensure that it is being followed.)

‘This is Me’: We recommend that each person with dementia fills in this optional leaflet. It provides detailed information about a person’s likes, dislikes, hobbies, and biography. He/she may need some assistance from a carer or relative.
(Tip – Keep the original document safe at home and make copies to give to staff whenever you need to come to hospital.)

The Carer’s Passport: This document recognises the value of the care, support and knowledge that a carer may provide for a patient with dementia during their hospital stay. It encourages our staff to value and support each person’s carers, to welcome them as active members of the care team, and to support their visits.
(Tip – Keep your Carers’ Passport with you at all times.)

Carer’s Survey: The questionnaire attached to this leaflet invites you to express your views. They will inform our practice and bring about change. Please return the completed form to a member of the ward staff.
(Tip – Be open and honest – your comments and suggestions could make a real difference.)

General advice

Medical Checklist. A doctor will use this detailed list to ensure that all aspects of medical care are checked daily.
(Tip – Notify staff of any changes in the patient’s usual behaviour, e.g., not as alert as usual, seeming agitated, or seeing things that aren’t there.)

Keep things normal. Ensure that the patient uses their dentures, glasses, and hearing aids as much as possible while in the hospital. Be guided by staff members.
(Tip – Where possible, put a name or initials on items to avoid items being mislaid.)

Personalise the patient’s environment. Familiar items such as photo albums, a favourite stuffed animal, a blanket from home, or activity they enjoy can alleviate anxiety commonly experienced in the unfamiliar hospital environment. Please consult staff first about the items you wish to bring in.
(Tip – Try to make sure they are labeled / initialed somewhere if possible and bring in copies of photographs rather than originals.)

If things are not going to plan or you have concerns, speak to a member of staff.

Going home and support through First Contact:

There are a number of ways that you and/or your carer can be supported on returning home, e.g., advice with benefits, home emergency alarms, having a key safe fitted, local support groups. First Contact can advise on where to get help with these and much more – please see the contact numbers below.

First Contact - for help and support at home

First Contact staff will be pleased to provide you with information, advice and direct you to services available to you locally in your area. Simply ring: 020 8408 8170
9am – 5pm weekdays or leave a message and they'll get back to you

For more information:

There are also a number of national organisations where you can find out more information:

- Alzheimer’s Society: Helpline 0300 222 1122
  Advice, information and guidance for people with dementia and their carers. A range of factsheets are available as well as a “The Dementia Guide, Living well with dementia”, an online chat room and signposting to local support services. Ask for the contact details of the local Alzheimer’s Society Office.

- Dementia UK: 020 7697 4160
  For more information and advice for people with dementia and their carers.

- Carers Trust: 0844 800 4361
  Ask for the contact details of your local Carers Centre

This leaflet has been produced in partnership with Age Concern Kingston, Alzheimer’s Society SW London Office, Kingston Hospital Patient Assembly, and Adult Social Care at the Royal Borough of Kingston.

For review July, 2014 by the Service Improvement Lead for Dementia
The Pilot Project
A Dementia at Home Navigator Volunteer 3-month pilot role was created to improve support for patients with dementia and/or their carers during their stay in Kingston Hospital and to help signpost patients and carers to community resources via Age Concern Kingston’s First Contact phone number. Community resources vary according to which of five boroughs a patient is from. A need to help patients and carers to navigate this while meeting the below CQUIN standards was identified.

National Standards: “The provider must demonstrate that plans have been put in place to ensure that for every person who is admitted to hospital where there is a diagnosis of dementia, their carer is sign-posted to relevant advice and receives relevant information to help and support them” (CQUIN 2013/14) and “must test whether they feel supported via monthly audit” (CQUIN 2014/15).

The Role
• 3 hours one afternoon each week on hospital medical wards (26.02.2014-22.05.2014)
• Identified patients with dementia and their carers through the Forget Me Not scheme
• Provided basic information either in person or over the phone about dementia and accessing community services via Leaflet and First Contact phone number
• Collected Carer’s Surveys enclosed in the Leaflet

Leaflet
• Tips for carers to support their family member whilst in hospital
• Opportunity to complete a Carer’s Survey regarding hospital experience
• Promotes First Contact, a phone number provided by Age Concern Kingston as a single point of contact for patients and/or carers to call to find out about borough-specific services that are available to them.

Volunteer and Carer Feedback
• Many carers valued discussing their experience with the Volunteer
• However, carers frequently felt the First Contact referral was inappropriate since hospital admissions frequently occurred at later stages of the dementia journey. Carers felt signposting to community support would be most relevant immediately after diagnosis in primary care.
• Many patients did not have a carer or next-of-kin
• Afternoon shift – patients were frequently unavailable (sleeping, undergoing investigations or attending activities. However, carers were easiest to access in the late afternoon
• Ringing carers via cold calls was difficult. Often dementia was just one concern among many co-morbidities

Findings
• 65 patients with dementia or carers were approached by Volunteer in person or via phone across 9 hospital wards
• 35 phone messages were left for carers
• 12 Leaflets were provided directly to carers face to face
• 12 Carer’s Surveys were collected from 5 different medical wards
• 8/12 responded “yes” they felt adequately supported
• First Contact received 5 phone calls from Volunteer’s referrals over 3 months. Calls lasted between 5-30 minutes in length.

Next Steps
• Encourage volunteer organisations and commissioners to support similar volunteer or formal roles in primary care to ensure appropriate support and information are provided at diagnosis, or at an earlier stage in the dementia journey where community resources can be better utilised.
• Kingston Hospital will continue to develop Dementia Volunteer roles to support carers by distributing information leaflets, collecting Carer’s Surveys, and providing practical and emotional support to patients and carers in hospital.

- First Contact referral inappropriate since hospital admissions frequently involved people at the later stages of their dementia journey
- Carers felt signposting to community support would be most relevant immediately after diagnosis, in primary care/CMHT for older people
- Many did not have a carer or loved one
- Ringing carers was difficult. Often dementia was just one of their concerns amongst the person’s many other co-morbidities
Create the future of dementia care at Kingston Hospital

Have your say in improving dementia care

Date: Mon 23 Sept (9am & 2pm)  
Venue: Kingston Hospital, Education Centre

Objective
To create the future of dementia care for people at Kingston Hospital. Together, we can create a clear, shared view of how the care of people with dementia can be improved.

Attendees
Patients, carers, doctors, nurses, therapists, other staff from the hospital, partner organisations, general practitioners, voluntary organisations, and commissioners.
Anyone who wants to make a difference to the quality of care we provide to people with dementia.

Agenda
Introduction by leader in the field of dementia
Patients, carers and health professionals will work together in small groups to redesign care of people with dementia at Kingston Hospital.
Their discussions will focus on four key topics e.g. building respectful relationships, creating a safe and calm environment, or involving families in care. For each key topic we will:
* Hear patient and carer perspectives
* Be inspired by best practice from Kingston, the NHS and internationally
* Discuss and agree priorities for Kingston
The session will close with a discussion about what we can do to put these priorities into practice

Please register to attend:
www.kingstondementia.eventbrite.co.uk
To make it easier for people to attend, the conference will run twice 9am -12.30 and 2pm - 5.30. The agenda will be the same in the morning and afternoon.
Communication with patients, carers and family members

Individualised care from pre-admission through to post-discharge

Realise they live in the moment

Activities the patient enjoys

Training and dementia awareness

1:1 life story Focus on what they can do

Spend more time with patients and carers

Familiar environments Compromise, empathy, dignity and patience

Own clothes

Consistency Key worker

Dementia champions Link nurses

Joint work with carers

More staff More time

Complicated communication and jargon

Noise, shouting

Repeating patient's story

Eating alone

Confusion

Boredom confined to bed Institutionalization

Paperwork Inflexibility ward routines visiting times

Anti-psychotics

Rushing about

Task-oriented care

Expecting people to conform to 'standard' behaviour

Challenging things that don't matter

Making assumptions and labeling people with dementia
• Early diagnosis, excellent treatment and care

• Positive relationships of care

• Involved and supported carers

• Active days and calm nights

• Environments of care
Our mission for dementia care at Kingston Hospital

To improve the health and well-being of our community through the provision of high quality, patient focused healthcare

Care relationships and staff skills
- A culture of excellent, compassionate care that gives our patients and their carers confidence
- Staff who are confident in their role and how to deliver excellent dementia care
- A care team of experts in dementia recognised as experts in the subject that others come to for advice
- Our staff
  - Recognise dementia and delirium and know what to do for their patients
  - Know where to go for support when they need it and support available when it is needed
  - Have all had face to face training in dementia

Environments of care
- Our environments will be safe, warm, homely, comfortable and facilitate all types of bathing
- All staff will know what a dementia friendly environment is
- We will have, and receive approved additional funding for improvements in our environments
- We will protect staff and therapeutic environments
- Signs and pictures throughout the Trust will be dementia appropriate

Active days and calm nights
- When well enough to do so, our patients will be out of their beds, wearing their own clothes, walking around safely and engaging in meaningful activities
- Patient routines will be maintained despite them being in hospital
- Staff will have the skills to support active days and calm nights

Involving carers
- We will:
  - Engage, actively welcome and involve carers as partners in care
  - Support and involve carers in care planning, especially at important transition points (e.g. discharge)
  - Recognise and address the needs (and changing needs) of carers
  - Will be a leader in care involvement, recognised nationally

Diagnosis and clinical care & treatment
- We will:
  - Diagnose dementia and delirium at the right time, in the right setting, in the right way
  - Provide the right support afterwards
  - Actively prevent delirium and manage it effectively when it occurs

Guiding principles (Values)

[Icons representing values]
Complexity of ageing
<table>
<thead>
<tr>
<th>TIME</th>
<th>MONDAY</th>
<th>TUESDAY</th>
<th>WEDNESDAY</th>
<th>THURSDAY</th>
<th>FRIDAY</th>
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</thead>
<tbody>
<tr>
<td><strong>EARLY MORNING</strong></td>
<td>Movement &amp; Exercise 8.30am-9.30am (physiotherapy department)</td>
<td>Movement &amp; Exercise 8.30am-9.30am (physiotherapy department)</td>
<td>Movement &amp; Exercise 8.30am-9.30am (physiotherapy department)</td>
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<td>Movement &amp; Exercise 8.30am-9.30am (physiotherapy department)</td>
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<tr>
<td>AM</td>
<td>Reminiscence Therapy 11am-11.45am OR 1:1 Intervention</td>
<td>Hairdressing Experience 10.30am-12.00pm (fortnightly)</td>
<td>PAT Dog Therapy 10.30-11.30am</td>
<td>1:1 Intervention 10.30am onwards</td>
<td>Art Therapy 10.30am-11.45am</td>
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<td></td>
<td></td>
<td>Memory Lane Lunch Club 12.15pm-13.15pm</td>
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<tr>
<td>PM</td>
<td>Games 14.00pm-15.00pm</td>
<td>Reminiscence Therapy 14.00-14.45pm</td>
<td>Singing / Music Group 14.00-15.00pm</td>
<td>Cinema Club (Old movies black &amp; white) 14.30pm</td>
<td>Aroma Therapy / Relax/Sensory Experience 14.00-15.00pm</td>
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<td></td>
<td></td>
<td>MEMORY CAFÉ 14.00-16.00pm (fortnightly)</td>
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<tr>
<td>EVENING</td>
<td></td>
<td>Story Telling 16.30-17.00pm</td>
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</tbody>
</table>
Patients Mood

Please circle the number that reflects PATIENTS mood BEFORE the activity, please ask patient to point to number on card:

10 10
Very Very
9 Content Content
8 Uncontent Uncontent
7
6
5
4
3
2
1

Your Mood

Please circle the number you think best reflects YOUR mood BEFORE the activity:

10 10
Very Very
9 Content Content
8 Uncontent Uncontent
7
6
5
4
3
2
1

Please circle the number that reflects PATIENTS mood AFTER the activity, please ask patient to point to number on card:

10 10
Very Very
9 Content Content
8 Uncontent Uncontent
7
6
5
4
3
2
1

Please circle the number you think best reflects YOUR mood AFTER the activity:

10 10
Very Very
9 Content Content
8 Uncontent Uncontent
7
6
5
4
3
2
1

Pre/Post Activity Mood Ratings
Staff and Patients (n=136)

Pre Activity Patient Average (/10)
Post Activity Patient Average (/10)
Pre Activity Staff Average (/10)
Post Activity Staff Average (/10)
Kingston Hospital to double volunteer force following funding boost

This work is supported by Nesta as part of the Centre for Social Action Innovation Fund, in partnership with the Cabinet Office.
Volunteer Awards 2015
Nomination Form

Who are you nominating?
Name of individual: ...........................................

Their role: ...................................................

Department and Contact Tel no: ...........................

Under which value are you nominating (please circle):
Caring    Safety & Wellbeing    Responsible    Value Each Other    Personal Impact

Why should the individual/team receive this award? (maximum 200 words)
(Please turn over to select the value criteria to write your)

Your name and contact details
Name: ..........................................................
Job Title: ....................................................
Department: ............................................... 
Contact No: ................................................

Please read the following section & sign below
The information I have provided on this form is correct to the best of my knowledge. I understand that the judging panel may contact me if they require any additional information. The judges’ decision will be final and no correspondence will be entered into. I understand that nominations may be published.

Signed: ...........................................
Date: ............................................

Please email completed nominations to volunteering@kingstonhospital.nhs.uk or paper copies to Richard Coxon, Volunteers Services Manager, Davies Wood House – Annex.
Feeding difficulty in older adults with dementia
Chang CC, Roberts BL

A volunteer feeding assistance program can improve dietary intakes of elderly patients – a Pilot Study
Walton K, et al

Additional feeding assistance improves the energy and protein intakes of hospitalised elderly patients. A health services evaluation
Manning F, et al
1. INTRODUCTION
- Antipsychotic use in people with severe behavioural and psychological symptoms of dementia (BPSD) carries an increased risk of mortality, with only modest efficacy.
- There is a national drive to decrease antipsychotic use in BPSD.
- NICE (2014) recommends that, if antipsychotics are prescribed, there should be full discussion and documentation of the risks and benefits, documentation of the target symptoms, and regular review.
- Our annual local anti-psychotic audit showed that our rate of prescriptions had halved, and documentation of target symptoms and review of prescriptions had improved threefold since previous years' audits.
- However, in no patients were the risks and benefits of prescribed antipsychotics discussed with patients or relatives, family members, or carers.
- We used the 'Learning to make the difference' quality improvement model to facilitate discussion and improve communication and information for patients and their carers.

2. KEY RISKS
- Loss of trust from patients and their carers
- Inappropriate prescriptions and review of antipsychotic medications
- Increased patient morbidity and mortality

3. QIP AIMS & FINANCIAL DETAILS
The QIP aims to improve discussions with patients and relatives when antipsychotics are prescribed for people with BPSD, and to improve the documentation of those discussions.
- Costs include: stickers and leaflets
- Time taken to train and increase awareness for many staff groups

4. KEY PERFORMANCE INDICATORS
>80% of patients with dementia on antipsychotics to have full documentation of:
1. The discussion of risks and benefits of the drug with patients and/or families and carers, including the use of the Patient's and Carer's Information Leaflet
2. Indication for the prescribed antipsychotics
3. The drug being reviewed and a review date set

5. CHANGE
1. Staff Education
   - Psychiatric liaison team - 10/11/13
   - Medical doctors/Grand Round - 11/11/13
   - Elderly Care Department - 14/03/14
   - Pharmacist meetings - 12/11/13 & 30/11/13
   - Nursing Staff - ongoing
   - New Blue Book guidelines for 2013

2. Patient's and Carers' information leaflet
   - Information leaflet for patients and their carers

3. Drug chart stickers + E-prescribing prompts
   - Antipsychotics in Dementia Patients
   - Antipsychotics in Morbid Dementia Patients
   - Antipsychotics in Delirium
   - Antipsychotics in Dementia Patients
   - Antipsychotics in Dementia Patients
   - Antipsychotics in Dementia Patients
   - Antipsychotics in Dementia Patients

6. RE-AUDIT
- First pilot re-audit showed significant improvement (30-50%) in discussing risks and benefits but not yet meeting the 80% target.
- Small sample size from spot audit.

8. CONCLUSION
- This ongoing QIP has started to improve practice locally through increased awareness and better documentation of communication with patients and relatives. This is in line with the national drive to improve dementia care.
- Our results show that significant improvements can be made using a structured QIP model; however, challenges include ongoing sustainability and further improvements.

7. LIMITATIONS TO PILOT
- Education occurred before doctors and pharmacists changed rotation and information was not handed over.
- Changing location of stickers - now located in dementia boxes on each ward.
- Small sample size from spot audit.
Memory Café

People with memory loss, Alzheimer’s and other dementias and carers are all welcome.

Our first one is on Tuesday 20 January 2015, 2pm-4pm

Every other Tuesday Afternoon, 2pm-4pm at Kingston Hospital, back of the restaurant, Kingston Surgical Centre.

A Memory Café offers people with dementia and carers the chance to socialise and share information. We are working with Home Instead to bring this free event to Kingston Hospital.

Tea, Coffee, Cakes, Games, Music, Dance, Art and Crafts.

For more information, please call 020 8934 2800 or email claire.wright@kingstonhospital.nhs.uk
What have we achieved?

- Change in culture
- 100% aware – achievable
- Patients’ and carers’ experiences of care in our hospital are important. Hearing their experiences is vital
- Carers and volunteers make the difference for our patients in our hospital