Dementia strategy 2017-19
Surrey & Sussex Healthcare NHS Trust
Working to become a dementia friendly organisation

Developed by: The dementia strategy steering group
Launched May 2017
Introduction and Context

Introduction

At Surrey and Sussex Healthcare NHS Trust we have developed a dementia strategy to ensure that people with dementia or memory problems are given the support they need and are cared for with dignity, respect and compassion. Our strategy is for all people living with dementia regardless of their age and will build on a number of dementia initiatives that have been developed within the Trust. It will also fit with the Trust’s vision of safe, high quality healthcare that puts our community first.
The strategy covers all aspects of care for patients living with dementia during their time with the Trust, whether inpatient or outpatient and also recognises the needs of their relatives and carers. Our Strategy acknowledges the importance of working as one team within the Trust as well as working with other partner organisations to ensure that we provide excellent person centred dementia care. In order for this strategy to meet its aims it will be overseen by a multi-disciplinary Dementia Strategy Steering Group (DSSG), which will include Trust staff and professionals from partner organisations. The purpose of the DSSG is to oversee the local implementation of the Trust’s Dementia Strategy and to enable and oversee developments that will improve care that patients with dementia receive. (See terms of reference for DSSG, Appendix 1). The DSSG will explore developing the group into a Dementia Action Alliance, linking the Trust to national dementia objectives. Dementia Action Alliance brings together organisations and individuals across the local community committed to improving health and social care outcomes for people living with dementia, and those who care for them.

The overall aim of this strategy is to work become a dementia friendly organisation and will focus on four key areas, the patient experience, engagement, training developments and the environment. We believe that many of the principles of this strategy will not only benefit people living with dementia but all patients and their carers who use our services. The Trust’s Dementia Strategy will work towards the NICE (2006)¹ guideline on Dementia (CG42) to ensure it meets the principles of care for people with dementia by using the baseline assessment tool.

**The National Context**

The increasing number of people living with dementia is a challenge to all health and social care organisations. There are approximately 850,000 people living with dementia at present². There is evidence that each year the number of people living with dementia is growing and future predictions suggest that there could be up to 40% of people over 65 in hospital beds living with dementia.³

Our dementia strategy is aimed at all people living with dementia regardless of their age. Prevalence of *young onset dementia* in the UK *under 65* is estimated to be 42,325 people (5% of all people diagnosed with dementia).

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² Alzheimer’s Society (2014), *Dementia 2014: Opportunity for change*

³ Care Quality Commission (2014) *Cracks in the Pathway*
This strategy has used the following national policies as the framework for structuring development activity over the next three years; The Prime Ministers Challenge on Dementia 2020\textsuperscript{4}, National Audit of Dementia Care in General Hospitals, Dementia Action Alliance, Dementia Friendly Hospital Charter (2014) and Alzheimer's Society Fix Dementia Care Hospital (January 2016)\textsuperscript{5}.

**Local Context**
East Surrey & West Sussex have an older population with a greater life expectancy compared to the national average. At East Surry Hospital data taken form admissions during 2015-16 found that of the 90,100 admissions approximately 25% (21,650) where 75 and over. Based on rates of dementia in in the UK would mean that approximately 21% (4540) of this age group population will also be living with dementia.

The Trust’s Dementia Strategy will link with the Trusts dementia and delirium Standard Operating Procedures and will also support other relevant strategies and policies including; Education and Development, Patient Experience, Carers Strategy, End of Life Policy and the Trust’s Values and Vision statements. It will also reflect the aspirations of the local and nationwide dementia strategies.

**The Dementia Strategy Steering Group**
As part of the Dementia Strategy a steering group has been set up, its purpose is to oversee the local implementation of the Trust’s Dementia Strategy and to ensure developments that will improve care that patients with dementia receive are implemented and evaluated. The group is made up of Trust staff and external partner organisations. The group will review the Standard Operating Procedures that will support the Dementia Strategy’s aims and will link with the dementia, delirium, stroke and fractured neck of femur pathways.

\textsuperscript{4} Department of Health 2013 National Dementia Five Year Strategy
Department of Health (2016)Prime Minister’s Challenge on Dementia 2020: Implementation Plan

\textsuperscript{5} Alzheimer’s Society (2016), Fix Dementia Care :Hospitals
Working to become a dementia friendly organisation

Patient experience

- We aim to ensure that patients with a diagnosis of dementia, memory problems or delirium are identified on admission or at out-patients and pre-assessment appointment, so that the service meets their individual needs and can provide appropriate support and information to their carers/families.

- We will review the dementia and delirium screening tools used on admission and support the use of these tools to be used for all patients over 75 admitted to the Trust. This will allow our staff to identify people with undiagnosed dementia or delirium and inform their GP so a referral can be made on to the appropriate community mental health memory services or liaison psychiatry services for advice on appropriate treatment. We will ensure that patients diagnosed with dementia or have suspected dementia and/or their family/carers are offered the right support and information.

- We will review the dementia pathway and ensure that it links with the Delirium, Stroke and Fractured Neck of Femur pathways.

- The Dementia Strategy Steering Group will be responsible for the overview of the “Annual Statement” for dementia. This will include; reporting on the following:
  - satisfaction levels from patients with dementia and their carers (taken from the Trust Friends & Family Test and comments from Patient Opinion),
  - Review the number of falls of people with a dementia diagnosis.
  - Review the number of inappropriate discharges, (i.e. for people with a dementia diagnosis being discharged between 11pm and 6am, with less than 24 hours’ notice or with significant delays),
  - The number of people with dementia being prescribed antipsychotic drugs.
  - Demonstrate examples of how care is being personalised (use of Reach-Out To Me” or “This is Me”.

- We will review the food service, and this will include the development of a finger food menu, trial the use of blue plates, review use of protected meal times and the use of meal time volunteers.

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6 Alzheimer’s Society (2016) Fix Dementia Care : Hospitals
We will aim to improve the management of pain in people living with dementia. We will promote the use of the Abbey pain tool as a method of measuring pain where someone may have communication difficulties due to their dementia or delirium.

Engagement

- Across the whole Trust we will aim to ensure that patients are offered the opportunity to be part of the Butterfly Scheme. Where a patient is unable to consent to the scheme and no family is available to advocate on behalf the patient the MDT will make a decision to be part of the scheme if it felt to be in the patient’s best interest.

- The Butterfly Scheme was developed by a carer of a person living with dementia and has been introduced to hospitals across the country. The Butterfly Scheme promotes personal choice; people opt to use the scheme and that opt-in represents their request for a specific, personalised care response. Its aim is to improve patient wellbeing by ensuring staff offer a positive and appropriate response to people with memory problems. People who opt into the scheme are identified via a discreet butterfly symbol on their notes and or by the bedside.

- We aim to have identified dementia lead(s) in all clinical areas across the Trust; their role will be to ensure the Butterfly Scheme is embedded in the clinical area and support colleagues in signposting patients and carers/families to it. The Dementia Leads will be offered the opportunity to attend the dementia leads training (3 days) and attend regular dementia leads meetings. Regular updates on the strategy will be published and shared through the dementia leads networks. The Dementia Leads will also be the point of contact for the clinical area regarding dementia updates, research and audits.

- We will provide personalised care by ensuring that patients and/or their carers are offered a copy of either “Reach Out To Me” or equivalent pro-forma that provides information pertinent to caring for the person with dementia. Staff will support the patient, carer and/or the family to complete these.

- We will work in partnership with carers, the Trust recognise that relatives and carers of patients with dementia in hospital are a valuable resource that can provide invaluable information about their relative for care planning. We aim to ensure our carer engagement follows the principles of the Carers UK, Triangle of Care for Dementia.

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The Trust has introduced a “Carers Passport” and adopted “Open Visiting”. The Trust has signed up to The John’s Campaign. The aim of the campaign is to give the carers of those living with dementia the right to stay with the person and continue to provide support while they are in hospital.

Training and Developments

- Dementia Friends sessions will be part of Trust induction and on-going MaST Training. Dementia Friends awareness sessions has been adapted and approved by The Alzheimer’s Society to include Tier 1 Dementia training (Health Education England). The Dementia Friends programme is an initiative to change people’s perceptions of dementia. It aims to transform the way we think, talk and act about dementia.

- Develop dementia training for the Trust’s dementia leads providing more detailed information on a number of aspects of dementia, including, pain management, communication, managing and understanding behaviours that challenge, nutrition and hydration as well the impact of dementia from patient and carers perspective.

- Identify educational opportunities available for staff offered through the Kent, Surrey & Sussex Academic Health Science Network, Surrey and Brighton Universities. Link with the Trust’s Education and Development Department to ensure that the dementia training is included in commission decisions.

- Research; the Dementia Strategy Steering group will link with the research department and will consider research requests that impact on the experience of people living dementia.

- New technologies and initiatives, the DSSG will consider and support new technologies and initiatives that impact on patients with dementia experience. This will include reviewing trials and providing feedback.

The Environment

- The Trust will aim to develop dementia friendly environments in order to transform the patient’s experience while in the hospital as either an out-patient or inpatient.

- All new buildings and re-developments across the site will always be assessed to ensure that it meets dementia friendly standards based on the Kings Fund Healing Environment Design.
Principles\textsuperscript{8} and work developed by Stirling University Dementia Services Development Centre\textsuperscript{9}. The DSSG will be made aware of any new developments and will aim to be involved in the design phase.

- We aim to ensure that signage, way finding and art work meet dementia friendly standards.
- Review and act on the feedback from the Annual PLACE audits (Patient Led Assessment of the Care Environment). The audit includes an audit of the environment from a dementia perspective.

**Review and Measuring Improvements**

**Strategy review**

The strategy is a living document and will be reviewed by the DSSG and updated to reflect changes in local or national polices. The document will be reviewed by April 2019.

**Measuring and improving dementia care at Surrey & Sussex Healthcare Trust**

We will listen to our patients, carers and staff and continually strive to improve our care for patients with dementia. We will know that we are achieving our standards by regularly measuring the differences we are making to patients with dementia, carers and staff. In addition to the ‘Friends and Family Test’ and ‘Patient Opinion’. The DSSG we will oversee and review key performance indicators that we will share with our patients, staff, commissioners and the public.

- Regular review of progress and evaluation with the Dementia Strategy via the Dementia Strategy Steering Group
- Annual PLACE report
- Increasing the numbers of staff trained in dementia awareness
- All clinical areas have an identified dementia lead
- Increasing carer satisfaction rates
- Reduction in complaints related to care of patients with dementia
- Reduction in length of stay
- Reduction in delayed transfers of care
- Reduction in number of falls of people with dementia
- Reduction in prescribing of antipsychotics for patients with dementia
- Increased nutritional intake

\textsuperscript{8} The Kings Fund (2013) Improving the patient experience: developing supportive design for people with dementia.
\textsuperscript{9} DSDC (2012) Dementia Design Series: Design features to assist patients with dementia in general hospitals and emergency departments. University of Stirling, UK.
## Dementia Strategy objectives action plans

Working to become a dementia friendly organisation

### The dementia strategy steering group

The following objectives will be overseen by the Dementia Strategy Steering Group (DSSG)

<table>
<thead>
<tr>
<th>Area</th>
<th>Actions</th>
<th>Date</th>
</tr>
</thead>
<tbody>
<tr>
<td>Develop the Dementia strategy steering group</td>
<td>Develop a Dementia Strategy Steering group that includes members of the multi-disciplinary and with partner organisations.</td>
<td>Established July 2016</td>
</tr>
<tr>
<td>Establish the Dementia Strategy Steering Group as a Dementia Action Alliance.</td>
<td>Discuss with the Alzheimer’s Society / Dementia Action Alliance the requirements of developing the DSSC to a Dementia Action Alliance and link with local DAA.</td>
<td>April 2017</td>
</tr>
<tr>
<td>NICE (2006) guideline on Dementia (CG42)</td>
<td>The DSSG will ensure that the NICE (2006) guideline on Dementia baseline assessment tool is reviewed on an annual basis and updates will be shared with the Governance department.</td>
<td>Annually as part of DSSG meeting</td>
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### Objective

**Patient experience**

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<tr>
<th>Area</th>
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<tbody>
<tr>
<td>Review the delirium and dementia screening tools.</td>
<td>The DSSG will ensure a tool to screen for dementia and delirium is selected and used across the Trust.</td>
<td>June 2017</td>
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</tbody>
</table>

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<table>
<thead>
<tr>
<th>Table</th>
<th>Description</th>
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<tbody>
<tr>
<td><strong>The screening will be promoted and included in teaching and induction.</strong> Also ensure any paper versions of the screening tool are incorporated in new electronic care record</td>
<td>September 2017</td>
</tr>
<tr>
<td><strong>Dementia pathway links to delirium, stroke and fractured neck of femur</strong></td>
<td>Autumn 2017</td>
</tr>
<tr>
<td><strong>Develop the Dementia Annual Statement</strong></td>
<td>September 2017 and annually as part of Trust Quality Account document</td>
</tr>
<tr>
<td>- satisfaction levels from patients with dementia and their carers (taken from the Trust Friends &amp; Family Test and comments from Patient Opinion),</td>
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<td>- Review the number of falls,</td>
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<tr>
<td><strong>Food and Nutrition</strong></td>
<td>Summer 2017</td>
</tr>
<tr>
<td>- Develop of a finger food menu.</td>
<td>Spring 2017</td>
</tr>
<tr>
<td>- Trial the use of blue plates,</td>
<td>Ongoing</td>
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<tr>
<td>- Review use of protected meal times and the use of meal time volunteers</td>
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</table>
## Managing Pain

- Embed the use of the Abbey Pain Scale, Provide training and updates.
- Ensure the Abbey pain Scale is incorporated in the new Electronic Care record

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| Embed the Butterfly Scheme| Continually promote the use of the Butterfly Scheme across the Trust, through training (Induction and three day dementia leads programme)  
|                           | Support the use of the Butterfly Scheme through the Dementia leads meetings | Ongoing       |
|                           | Progress will be overseen and reviewed by the DSSG                        |               |
| Dementia Leads            | All clinical areas will have an identified Dementia Lead and are encouraged to attend the dementia leads meetings. The dementia leads will assist with the roll out and embedding the Butterfly Scheme.  
|                           | The Dementia leads will receive updates from the DSSG                      | On going      |
|                           | Regular updates on the strategy will be published and shared through the dementia leads networks. | 4 times a year|
| Personalised care         | Ensure that patients with dementia or                                   | 6 monthly audits|

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**Engagement**

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| Personalised care         | Ensure that patients with dementia or                                   | 6 monthly audits|
memory problems are encouraged to complete a “reach out to me” document. The dementia lead will offer the document to patient or their families/carers to complete.

An audit of notes will be carried out twice a year (part of the National Audit for dementia plus a Trust led audit) to ensure that the personalised care plans are being completed.

Ensure that the personalised care plans will continue to be used when the Trust goes to electronic care record.

<table>
<thead>
<tr>
<th>Working in partnership with carers and raise awareness of Johns Campaign.</th>
<th>The DSSG will review and act on feedback from carers comments via Friends &amp; Family Test, Patient Opinion plus information from PALS and the Trust Carers lead. Ensure Johns Campaign is included in all dementia training. Ensure information is available on Johns campaign and Carers Passport and support.</th>
<th>Ongoing</th>
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</tbody>
</table>
## Objective

### Training and developments

<table>
<thead>
<tr>
<th>Area</th>
<th>Actions</th>
<th>Date</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dementia awareness and training programme</td>
<td>The DSSC will review feedback from dementia specific training and the numbers of staff attending. The DSSG will review content of dementia programmes and bespoke training</td>
<td>ongoing</td>
</tr>
<tr>
<td>Research opportunities</td>
<td>The DSSG will consider research opportunities that impact on the lives of people living with dementia.</td>
<td>On going</td>
</tr>
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</table>

## Objective

### The environment

<table>
<thead>
<tr>
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<th>Date</th>
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</thead>
<tbody>
<tr>
<td>Dementia Friendly Environments</td>
<td>The DSSG will review new developments and refurbishments to ensure they meet dementia friendly standards and design principles. This include the review of any wayfinding and signage developments.</td>
<td>ongoing</td>
</tr>
<tr>
<td>Way finding</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Feedback from PLACE</td>
<td>The DSSG will review feedback from the annual Patient Led Assessment of the Care Environments (PLACE) audits and ensure that recommendations from the dementia specific sections are actioned.</td>
<td>Annually &amp; ongoing</td>
</tr>
</tbody>
</table>
Appendix 1

Dementia Strategy Steering Group (DSSG)

Terms of Reference

Discussed and agreed at DSSG on 12/7/16

1. **Purpose of the Steering Group**
   The purpose of the Steering Group is to oversee the local implementation of the Trust’s Dementia Strategy and to enable and oversee developments that will improve care that patients with Dementia receive.

2. **Establishment**
   2.1. The Strategy Steering Group is chaired by the Nurse Consultant for Dementia (Chris O’Connor)
   2.2. The Clinical Lead is provided by the Dementia Clinical Lead (Dr Iain Wilkinson)

3. **Reporting**
   3.1. The agenda and draft minutes of the Steering Group will be agreed by the Chairperson and circulated to all Steering Group members
   3.2. Steering group will report to Clinical Effectiveness Group (TBC)

4. **Responsibilities**
   4.1. To oversee dementia training and awareness programmes for staff whilst improving the dementia knowledge and skills across the whole of the organisation.
   4.2. To drive the Dementia care agenda and Dementia Strategy within the organisation and to ensure compliance with the standards identified within the National audit of Dementia care in acute hospitals and N.I.C.E standards
   4.3. To ensure that care and standards are delivered through a collaborate approach and the development of an Integrated dementia pathway for patients through effective partnerships
between commissioning, and representative provider organisations, and independent / voluntary sector organisations

4.4. To oversee improvements to the hospital environment in order to become a Dementia Friendly Hospital.

4.5. Ensure that good dementia care practice and initiatives are acknowledged, shared and celebrated.

4.6. Oversee the Trust’s annual statement on the quality of dementia care.

5. **Membership**

   **Trust**
   - Consultant nurse for dementia (Chair)
   - Consultant physician
   - Senior nursing representation (nursing directorate)
   - Senior therapies representative
   - Carers lead representative
   - Physician associate representative
   - Matron representative
   - Ward manager representative
   - Facilities representative (feedback on PLACE assessments)
   - Capital projects and estates representative
   - Pharmacy representative
   - Communications representative

   **Non Trust members**
   - Carer groups representatives from Surrey and Sussex
   - Alzheimer’s Society Rep
   - Surrey and Borders Mental Health Trust Rep
   - First Community Rep
6. **Frequency of meetings**
   The Trust steering group will meet every two months

7. **Review of Terms of Reference**
   These terms of reference will be reviewed annually
   Discussed and agreed at DSSG Meeting on 12/7/16
## Document control

### Change history

<table>
<thead>
<tr>
<th>Version</th>
<th>Date (DD/MM/YYYY)</th>
<th>Author/lead</th>
<th>Job title</th>
<th>Details of change</th>
<th>Ratification body</th>
<th>Archiving location</th>
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</thead>
<tbody>
<tr>
<td>First draft</td>
<td>November 2016</td>
<td>Chris O’Connor</td>
<td>Consultant Nurse Dementia</td>
<td></td>
<td>Dementia Strategy Steering Group</td>
<td></td>
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<tr>
<td>Second draft</td>
<td>January 2017</td>
<td>Chris O’Connor</td>
<td>Consultant Nurse Dementia</td>
<td>Added time lines</td>
<td>Dementia Strategy Steering Group</td>
<td></td>
</tr>
<tr>
<td>Final version</td>
<td>February 2017</td>
<td>Chris O’Connor</td>
<td>Consultant Nurse Dementia</td>
<td></td>
<td>Executive Committee - Quality, Risk &amp; Clinical Care</td>
<td></td>
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