

Subject:	Dementia Services in West Norfolk
Presented by:	Dr Sue Crossman, Chief Officer
Submitted to:	Health Overview and Scrutiny Committee, July 16 th 2015
Purpose of Paper:	Consultation

Executive Summary:

Following two positive evaluations in May 2014 and January 2015 of the changes to dementia services in West Norfolk, the CCG Governing Body agreed at their May meeting to consult HOSC regarding the proposal to continue with the pilot model in place since August 2013, thereby closing the beds no longer in use at Chatterton House. The attached document describes the dementia services before and after the pilot commenced and outlines the benefits to people in West Norfolk as a result.

RECOMMENDATION:

HOSC members are invited to review the information presented regarding the outcome of the pilot community teams put in place in August 2013 to assess and support people living with dementia, comment on the proposal to make the arrangements permanent and to comment on the appropriate level of public engagement.

Health Services Overview and Scrutiny Committee (HOSC) Consultation Document (V12 – 1st July 2015)

1. Introduction

This document has been prepared by West Norfolk Clinical Commissioning Group (CCG), following proposals regarding dementia services in West Norfolk developed by Norfolk & Suffolk NHS Foundation Trust (NSFT) which provides mental health services for this area. It is our duty as commissioners to ensure that the services provided are the right services for our patients, and consider the views of our public on NSFT's proposals when necessary. West Norfolk CCG's Governing Body will make a decision on the proposals when we have heard what HOSC, patients, carers, families, the public and local healthcare professionals think.

This document has been co-produced with members of a Dementia Consultation Reference Group. This group includes patient representatives, members of the community, voluntary organisations, GPs and local healthcare professionals.

Services provided by NSFT cover the whole of Norfolk and Suffolk, but this document focuses on the development of dementia services in the West Norfolk area.

2. Who are we?

West Norfolk Clinical Commissioning Group (CCG) was established in April 2013; a clinically led organisation whose Governing Body is made up of local GPs, a hospital consultant, nurse and lay representatives, which is responsible for planning, designing and buying health and care services for the population of West Norfolk. This includes planning what services are needed and agreeing contracts with hospitals, community services, mental health trusts and other organisations, to provide that care for patients within the allocated budget (currently around £220 million).

The West Norfolk area covers 165,000 people.

West Norfolk CCG commissions (buys) the majority of healthcare services for the local population, including most secondary care (or hospital) services, and services from community and mental health providers.



We are not responsible for commissioning primary care (i.e. GP services, opticians or dentists) or specialist commissioning services which are those services provided from only a few relatively specialist centres (e.g. renal (kidney) services, neonatal services, burn care and specialist cardiac services).

We work very closely with other agencies to ensure that the services available in West Norfolk promote the best health outcomes, both in terms of healthcare services themselves and those linked services such as social care, housing and education, which have an indirect impact on individuals' health.

One of our main responsibilities is to make sure that our population receives safe and high quality services. West Norfolk CCG is made up of 21 GP practices in West Norfolk and we represent their views.

3. The national picture for dementia

In 2009, the National Dementia Strategy 'Living Well with Dementia' made dementia care a priority across the country. The aim of the Strategy was to ensure that significant improvements are made to dementia services across three key areas: improved awareness, earlier diagnosis and intervention, and a higher quality of care.

It set out three key steps to improve the quality of life for people with dementia and their family/carers:

- i) To make sure that there is better knowledge about dementia and remove the stigma that still exists. Dementia is not a natural consequence of ageing and a lot can be done to support people with the condition. In reality, a great deal can be done to help people overcome the problems of dementia, to prevent crises and to improve the quality of life of all involved.
- ii) To make sure that people with dementia are properly diagnosed. We cannot hope to address a person's needs fully, or those of their carers, without a diagnosis being made, appropriate information being given and effective intervention offered at an early stage.
- iii) To develop a range of services for people with dementia and their family carers, which fully meets their changing needs over time.

The Strategy was developed because shortcomings in the provision of dementia services in the UK had been highlighted. Dementia presents a huge challenge to society, costing the UK economy in excess of £26 billion per year. With people living longer it is estimated that in the next 30 years, the number of people living with dementia will double to around 1.4 million, with the costs increasing to over £50 billion a year.

While the numbers and the costs are daunting, the impact on those with the illness and on their families is also profound.

Locally, the national approach is being underpinned by the Norfolk Joint Dementia Commissioning Strategy 2009-2014, which was produced by NHS Norfolk, NHS Great Yarmouth & Waveney and Norfolk County Council and set the scene for dementia services across the whole county. It set out how major coordinated improvements across the joint working of health and social care would lead to positive changes, over a five year period, in the way people with dementia were perceived, treated and cared for locally.

The changes proposed in this document are one part of an evolving dementia service.

4. What do we know about Dementia?

Dementia is a long-term condition, which results in a progressive decline in how a person is able to function, including memory, reasoning, communication skills and the skills needed to carry out daily activities. Alongside this decline, individuals may develop behavioural and psychological symptoms such as depression, psychosis, aggression and wandering, which complicate care and can occur at any stage of the illness. Family carers of people with dementia are often old and frail themselves, with high levels of depression and physical illness, and a diminished quality of life.

There is evidence from across the country which suggests that the longer a person with dementia spends in a hospital setting, the worse the effects on their dementia symptoms will be, as it can dramatically affect the way they function on a day to day basis, and their ability to perform what we would class as 'normal activities' such as using a knife and fork. Therefore, it is believed that if a person living with dementia is treated in their own home, or within familiar surroundings, their recovery can be faster, more effective and it will help them maintain their independence for longer.

Dementia is also widely accepted as being as much of a social issue as it is a healthcare issue and as a result, many areas/localities are striving to become dementia-friendly towns and communities. West Norfolk is no exception, with Swaffham and now Downham Market being part of a project aimed at achieving dementia-friendly town status, which raises awareness of the issues facing people living with dementia within community settings such as, for example, hairdressers, shops and cafes.

5. Outline of the NSFT Trust Service Strategy

The Norfolk and Suffolk NHS Foundation Trust's (NSFT) Service Strategy 2012-2016 was developed by Trust clinical leaders in collaboration with service users, stakeholders, commissioners and staff after extensive discussion.

The Service Strategy sets out how NSFT's services and support functions will operate taking into account a number of challenges, including:

- the need to always be improving care for patients and their carers;
- the reduction in funding for the NHS across the whole country;
- the need for NSFT to be able to respond quickly to ever-changing medical research, patient and healthcare expectations;
- the introduction of competition to healthcare which means that some elements of what NSFT would have provided might now be provided elsewhere;
- the shift of responsibility for commissioning to the new Clinical Commissioning Groups, making GPs the customer for most of NSFT's services.

In setting out the changes, the Strategy aims to give stability and certainty to staff, service users, and carers.

In West Norfolk, NSFT proposed changes to services for people with dementia and those with other mental health problems, alongside complexities of later life. This new service is called Dementia and Complexity in Later Life (DCLL) and has been operating as a pilot service since August 2013. These changes also work alongside the out of hospital care and closer to home services which are part of the West Norfolk Alliance and Norfolk-wide Better Care schemes.

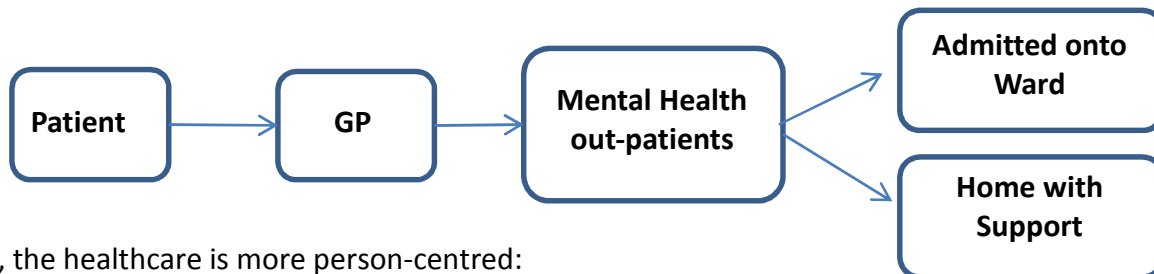
Dementia and Complexity in Later Life (DCLL)

As part of the proposed changes, community care has been improved. This service is for people of all ages with dementia and people with mental health problems who also have complexities associated with ageing. It stresses the importance of the early detection and start of treatment for dementia through a shared care arrangement with GPs. Intensive support teams provide rapid and intensive care for people with dementia or functional mental health problems (e.g. depression) to help them to stay at home for longer. Hospital acute assessment beds for people with dementia are part of the service. Discharge planning and alternatives to admission will always be sought to ensure that people are admitted to

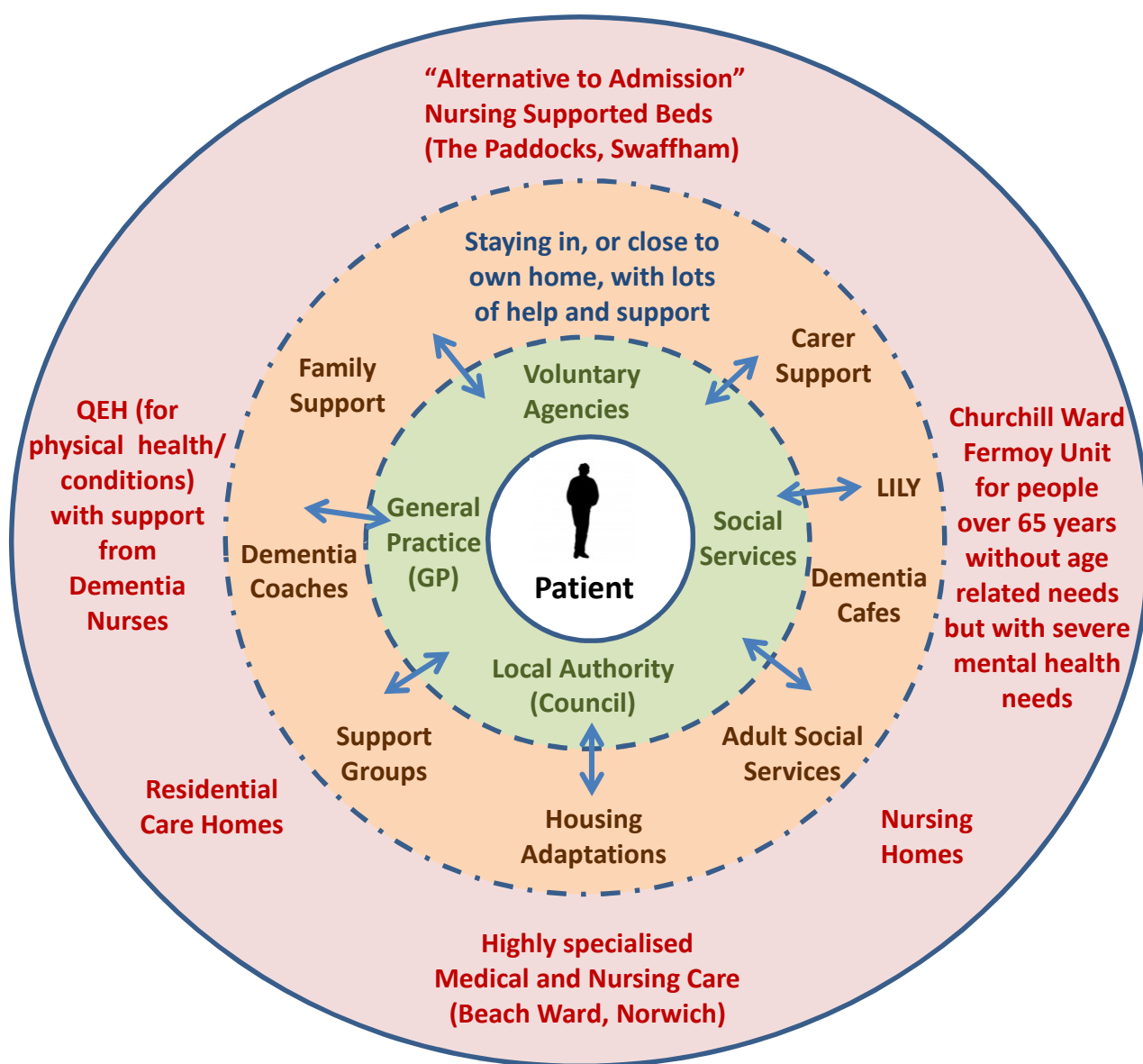
hospital only when necessary. Community staff will work within integrated care teams with social and community care staff.

6. How do these changes affect people who live in West Norfolk?

The Dementia Intensive Support Team (DIST) allows care for people living with dementia to move away from the more traditional medicalised model of healthcare:



Instead, the healthcare is more person-centred:



Before the West Norfolk Dementia Intensive Support Team (DIST) began in August 2013, there were two wards for older people - Chase and Tennyson Wards - at Chatterton House in King's Lynn. Together

these wards had 24 beds, although data from Norfolk & Suffolk NHS Foundation Trust shows that this number of beds was rarely used. Chase Ward provided 12 dementia assessment beds and Tennyson Ward had beds for assessing people who were over 65 years with other mental health problems. The purpose of these beds was for short-term use and assessing a patient's condition. They were not intended to be used for longer-term inpatient care, although patients often spent longer periods in them because access to community specialist care was limited. An initial DIST pilot in Central Norfolk provided evidence that the demand for dementia assessment beds would reduce and only those patients with very complex and acute needs would require an inpatient assessment. This indicated that 3 dementia assessment beds would be adequate for the needs of the West Norfolk population and consequently 3 specialist beds in Beach Ward at the Julian Hospital in Norwich have been designated accordingly.

It is important to note that the beds on Chase and Tennyson Wards were for assessment only and not for longer stay Continuing Health Care (CHC). NSFT has never provided or been commissioned to provide CHC beds in West Norfolk. The Trust's CHC provision has always been provided either at Carlton Court in Lowestoft, or in Norwich which has now been consolidated at Hammerton Court, a new unit at the Julian Hospital. This has contributed to the Julian Hospital being the centre of the Trust's Dementia Academy and recognised as a centre of excellence in the care of people with dementia and complexity of later life.

Throughout the pilot phase of the new DCLL pathway, the use of the West Norfolk in-patient beds has been suspended and the monies that would have funded them has been used in a different way:

- **The Dementia Intensive Support Team (DIST) has been established.**

The DIST provides assessment, treatment and intensive mental health community support to people with dementia and their care-givers and those with other complex mental health problems in later life.

- **There is support from 3 specialist (tertiary) inpatient beds.**

For West Norfolk patients who need highly specialist dementia care, 3 beds are available in Beach Ward at the Julian Hospital in Norwich. Here, patients have access to highly specialised treatment by a specialist mental health team and dedicated psychiatrist who are able to care for them in a purpose-built environment. This intensive short-term treatment would make it possible for the patients to return to their own homes, or a care home, in the shortest time possible.

- **There are 2 'Alternative to Admission' (ATA) beds available.**

A previous analysis of patients admitted to dementia assessment beds across the Trust showed that many did not require acute hospital admission, but were admitted due to lack of alternative options (e.g. increased community support as now provided by DIST or alternatives to hospital admission (ATA) beds). A fundamental element of the change to the pathways is therefore provision of local ATA beds and 2 have been commissioned at the Paddocks Care Home in Swaffham. This means that the patient is in a place where nursing staff are on hand to help. The DIST also supports patients using these beds by providing specialist support and treatment advice and prescribing to the Paddocks Care Home staff. A qualitative evaluation has taken place to inform this report which shows that service users and their care-givers are very positive about the use of the Paddocks as an alternative to hospital admission.

- **2 assessment beds are available patients with mental health problems unrelated to dementia.**

For West Norfolk people with, or who develop, age related needs or complexities in later life along with acute functional mental health problems, 2 assessment beds are available on the Sandringham Ward at the Julian Hospital in Norwich. Patients aged 65 years and over who do not have age related needs (complexities in later life) will continue to be supported by adult community services and if needing hospital care, will be admitted to an all age adult hospital bed in the Churchill Ward at the NSFT Fermoy Unit, on the Queen Elizabeth Hospital site, King's Lynn.

In order to help carers of West Norfolk patients who have been admitted to Beach and Sandringham Wards in Norwich, NSFT has money available to reimburse reasonable travel costs.

At the same time as the NSFT DIST model has been piloted, West Norfolk CCG has invested in more complimentary support services through the voluntary and community agencies that significantly enhance the care that people living with dementia in West Norfolk receive. This has led to our GPs having more confidence in the services that are available for their patients, resulting in a rise in their diagnosis, assessment and treatment. We have also invested in a programme of training to identify a number of Dementia Coaches across West Norfolk who can offer further support for people living with dementia and their families, which will also help to address the feelings of loneliness and social isolation experienced by some people living with dementia.

7. Comparison of activity before and after introduction of DIST

As a benchmark for comparison, activity on Chase and Tennyson Wards for the 6 months from August 2012 to January 2013, before implementation of the Trust Service Strategy has been used (see Table 1 below). This shows a total of 38 admissions during this period with an average length of stay of 86 days per episode of dementia care.

Table 1: NSFT Inpatient benchmark activity, August 2012 to January 2013 (26 weeks)

	Chase Ward	Tennyson Ward
Admissions	12	26
Shortest length of stay	10	1
Longest length of stay	145	183
Average length of stay	86	40
Total bed days *(estimate)	373	1040

* Total admissions x average LoS

Transition from using the beds on Chase and Tennyson to the new pathways took place gradually between September 2012 and July 13.

Chase Ward (12 beds), transitioned to: 2 Alternative to Admission (ATA) beds at the Paddocks Care Home, Swaffham and 3 Dementia Assessment beds at Beach Ward, Julian Hospital in Norwich.

Tennyson Ward (12 beds), transitioned to: 3 non-complexity in later life beds on the all age acute admission Churchill Ward at the Fermoy Unit, Queen Elizabeth Hospital, Kings Lynn and 2 complexity in Later Life beds at Sandringham Ward, Julian Hospital in Norwich.

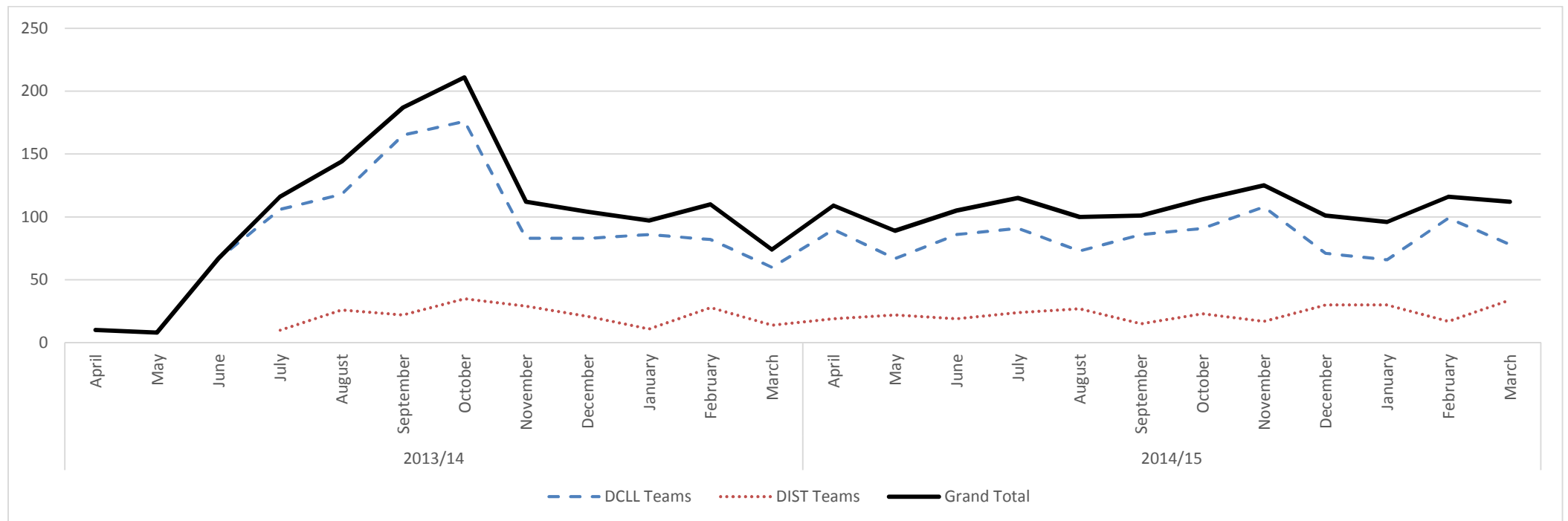
In the 9 months from fully establishing the DIST to April 2014 the team received 240 referrals, averaging 27 per month and maintaining an average active caseload of 33 (see Table 2).

7. The Clinical Evidence that supports this new way of working

Table 2 below shows the number of referrals to the DCLL and DIST Team in 2013/14 and 2014/15.

West Norfolk CCG Referrals to DCLL and DIST Teams in 2013/14 and 2014/15																								
	2013/14												2014/15											
	Apr	May	June	July	Aug	Sept	Oct	Nov	Dec	Jan	Feb	Mar	Apr	May	June	July	Aug	Sept	Oct	Nov	Dec	Jan	Feb	Mar
DCLL Team	10	8	67	106	118	165	176	83	83	86	82	60	90	67	86	91	73	86	91	108	71	66	99	78
DIST Team				10	26	22	35	29	21	11	28	14	19	22	19	24	27	15	23	17	30	30	17	34
Grand Total	10	8	67	116	144	187	211	112	104	97	110	74	109	89	105	115	100	101	114	125	101	96	116	112

Source : Local Dataset

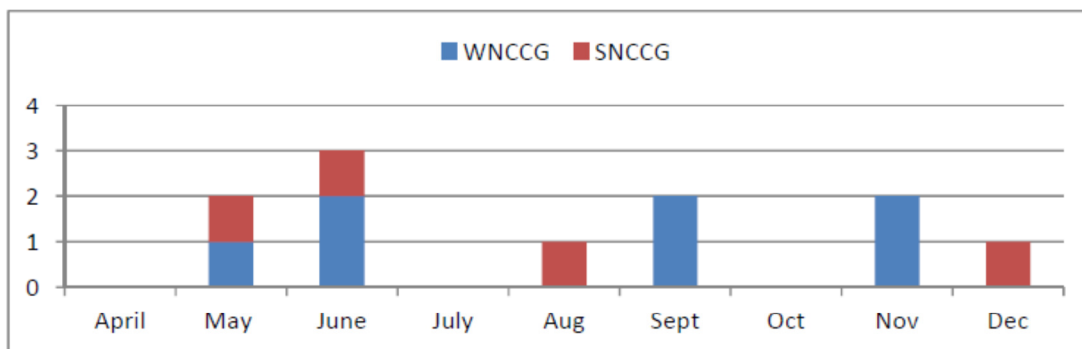


The most recent data available at the time of this report shows the admissions to Alternative to Admission beds (Table 3) and to Blickling Ward (now moved to Beach Ward) at the Julian Hospital (Table 4).

Table 3

Alternative to Admission (Paddocks Care Home) Bed Usage

Admissions & Discharges (April to 18th December 2014)

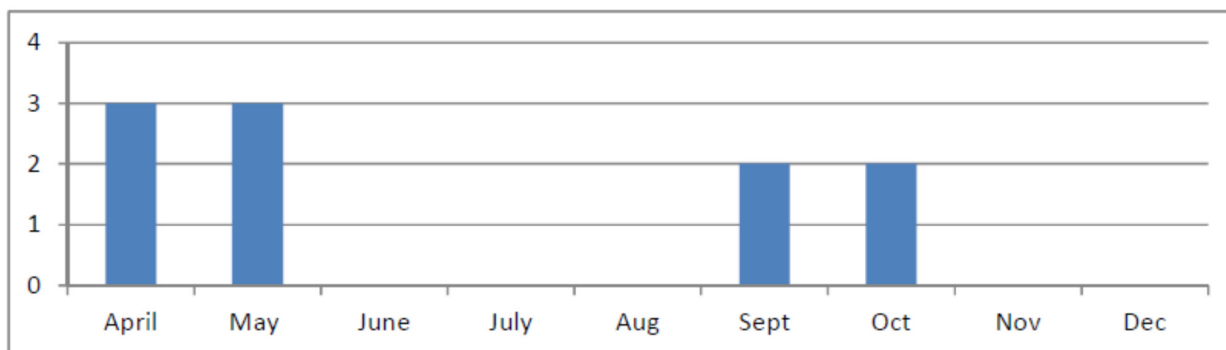


This graph shows a total of 11 admissions 4 of which were for residents of the Mid-Norfolk (SNCCG) are of the Norfolk West Locality.

Table 4

Blickling Ward, Julian Hospital, Norwich (Dementia Assessment)

Admissions (April to 18th December 2014)



This graph shows a total of 10 admissions of patients from the Wnccg area.

Of the 38 weeks between April and 18th December, 3 beds were occupied for 13% of the time, 2 for 24%, 1 for 29% and for 34% of the time, no beds were occupied by patients from the Wnccg area.

Average bed occupancy over the 38 weeks of patients from the Wnccg area = 1.2.

More recent data will be presented to HOSC at the meeting on July 16th. In summary, since the Dementia Intensive Support Team (DIST) became operational in August 2013, the team have:

- Received 668 referrals to the end of February 2015;
- 22 West CCG GP surgery patients were admitted to the Alternative to admission bed (ATA beds) at the Paddocks Care Home in Swaffham, between July 13 and end of February 15, with an average length of stay of 21 days.

- 26 West Norfolk CCG GP surgery patients in total have been admitted to the specialist dementia assessment inpatient facilities on Beach Ward in Norwich, with an average length of stay of 63 days. These numbers vary from month to month, with spells where all the beds are vacant.
- There is a trend of reduced admissions and length of stay, with increased activity in DIST team. This is likely to be a consequence of the increasing confidence and efficacy of the DIST and confirms expectations.
- The DCLL Community Team are seeing a much high number of referrals than at any time previously, the majority of them being for memory assessment and dementia treatment.

The model of community-based treatment and support is resulting in more patients being assessed and treated, fewer admissions to hospital and greater confidence in managing dementia in the community using a partnership approach to care.

A return to the 'old' model of in-patient beds in Chatterton House would mean that the DIST Team would have to be dismantled, in order to provide the necessary staffing levels. This would have a big impact on the support available in the community and the number of people living with dementia who can be treated in their own homes.

A case study is presented below to illustrate the experience of a patient and care-giver before and after the introduction of the community DCLL and DIST service.

Case Study

The following case study features a made-up patient and describes their journey as they travel along the DCLL pathway in West Norfolk.

Bob is 73 years old. He lives at home with his wife Vera. Bob has a diagnosis of Alzheimer's Dementia. Bob and Vera live in an isolated village several miles outside of Kings Lynn. They have no close neighbours and their son and daughter both live in London and work full time.

Vera has found it increasingly difficult to manage Bob at home. She has arthritis which causes her some problems with her mobility. Bob has developed some behavioural and psychological symptoms of dementia. Unfortunately Bob spent some time in a prisoner of war camp when he was younger and now when Vera is trying to care for him, he often believes Vera is a guard in the camp and he becomes scared and shouts at her and pushes her away from him. He is also no longer able to have full control of his bladder functions and often has accidents. Vera finds it hard to manage to help Bob with this and is finding it exhausting to keep up with the changing of the sheets and all the washing.

Bob's problems are often worse early in the evening when Vera is trying to help him get ready for bed. Carers come and try to help Vera and Bob, but Bob finds it hard to have these strange people in his house and after they have left, Vera finds it hard to cope with Bob.

Prior to changes

Vera tries to ring the team at Chatterton House, but no one answers calls after 4.30pm. She rings the GP who comes out to see Bob. The on call GP does not feel Bob has any physical health problems so he arranges for Bob to be admitted to the ward at Chatterton House.

Bob is on the ward with 15 other people, all who have dementia. Some of the people have more symptoms with their dementia than Bob does and he does not like it on the ward. Vera finds it hard every time she visits Bob as he keeps saying he wants to come home. Being in unfamiliar surroundings Bob quickly begins to lose skills he had at home, such as being able to assist in his own washing, dressing and making a cup of tea. He is also now incontinent more often as he has difficulty finding the bathroom. Bob gets increasingly distressed and is eventually discharged into full time care.



Now

Vera rings Bob's GP who comes out to see Bob on a Friday afternoon. The GP does not feel Bob has any physical health problems so he makes an urgent referral to the DIST team at Chatterton House. A qualified nurse from the team visits Vera and Bob at home on Saturday morning. The nurse spends a couple of hours with Vera and Bob investigating the difficulties they are having and undertakes a full holistic assessment. The DIST team are able to come back and visit Vera and Bob on the Sunday too.

They ask Bob's GP to prescribe him a low dose of medication which helps Bob with his worries about his past experiences in the camp. Over the following week they show Vera different ways of trying to help Bob, giving her confidence about how to keep him content whilst involving him in his own care, which makes the situation easier for her and Bob too.

The DIST team also talk to Bob's carers and they help them with ways to help Bob too. Vera is pleased as she and Bob are able to stay in the comfort of their own home, saving Bob the anxiety he feels if he has to leave the house and meet 'new faces'. Vera is also able to ring the DIST team in the evening when she feels worried about how Bob is and the DIST team can visit her and Bob up until 8pm and over the weekends too.

Vera and Bob's children feel happier as they know that people are supporting their parents at home and when they come up to visit their parents, the DIST team arrange to visit Vera and Bob while they are there and answer any questions they have too.

After three weeks, Bob is transferred to the community mental health team for further monitoring and review of medication and is then discharged back to the GP after two months. Vera was signposted to the Alzheimer's Society who were able to provide her with information on local sources of support and groups that were running, where she could meet other carers who were experiencing the same difficulties as she was.



8. What do the people living with dementia in West Norfolk and their carers say?

During 2013, West Norfolk CCG held a series of conferences and workshops to explore the patient and carer perspective of dementia services in our area. The initial conference, held in April 2013, was well attended and we were fortunate to have a number of people living with dementia and their carers who felt they were able to share their experiences. This gave us a powerful overview of how dementia services were accessed and what information was given when people and loved ones were diagnosed. At the end of the conference, patients and carers were invited to be involved in a series of work-stream meetings to look at specific issues. These work-streams were held from June to August.

i) The objectives of the Carer's Work-stream were to consider:

- how people with dementia and their carers recognise when and how to ask for information and support;
- how carers get 'substitute' or 'respite' care for shorter or longer periods of time and what needs to be improved;
- what other social care support is required as the health of the person with dementia declines;
- the support that is available from voluntary and community organisations and what support these organisations need from Statutory Services;
- how advanced care planning can happen even with difficult conversations about issues such as Lasting Powers of Attorney (health and welfare; property and financial affairs) and preferred place of care at the end of life;
- how West Norfolk CCG can involve to a greater degree other public sector organisations in support of carers.

The views of local healthcare professionals were also sought via a healthcare professional work-stream.

A list of the issues arising from these work-stream meetings can be found at Appendix 1.

The outcomes from those meetings formed the basis of an action plan which was discussed at a follow-up stake-holders workshop in September 2013, with outputs and outcomes outlining steps for West Norfolk CCG to take forward, with a view to leading the way in creating an integrated dementia-friendly community in West Norfolk.

9. What are we asking your views on?

West Norfolk CCG is seeking views from HOSC on the positive development of dementia services in West Norfolk since August 2013.

The NSFT TSS changes have been operational for 18 months as part of a pilot project. During that period, the evidence suggests that:

- There is a clear need for community based acute mental health services for the frail elderly and the new community service is reaching more people and reducing the distress of removing them from their familiar home environment;
- Where an admission is necessary, the length of stay is shorter than before

- The use of a range of services in the community and acute pathways ensures there are appropriate service user, carer and clinician choices in considering the best care and treatment option for patients;
- Service user and carer feedback and feedback from professionals indicates that the services are developing in the manner that meets needs and expectations and overall are perceived in a positive light.

The suspension of the in-patient beds at Chatterton House has made it possible for enhanced community mental health care provision through the setting up of the Dementia Intensive Support Team (DIST) and the Complexity in Later Life services which, in turn, has made it possible to treat more people in their own homes, or closer to home.

West Norfolk CCG is therefore proposing to make the closure of the beds on Chase and Tennyson Wards permanent. The CCG will continue to monitor closely the in-patient admission and length of stay data, as well as DIST and DCLL caseloads, to ensure that the capacity of the service is sufficient to meet the needs of the West Norfolk population.

HOSC is invited to comment on this proposal and the appropriate level of public engagement.

Glossary

Word or Phrase	Meaning
Accident and Emergency (A&E)	A&E departments assess and treat people with serious injuries or illness.
Acute Care	Short-term medical treatment in a hospital for very unwell patients.
Adult services	Adult services are for people aged 18 and over with mental health problems such as depression, bipolar disorder or schizophrenia.
Alternative to Admission (ATA) beds	Alternative to admission services offering service users effective alternatives to hospital admission and to reduce the length of stay where possible.
Clinical Commissioning Group (CCG)	Clinical Commissioning Groups consist of groups of GPs and other clinicians who decide on how NHS money is spent on healthcare services in their local area.
Clinicians	A health professional, such as a physician, surgeon, psychiatrist, psychologist or nurse, involved in clinical practice (caring for patients).
Community Staff	Healthcare professionals who work in the community, e.g. district nurses, physiotherapists, mental health nurses.
Consultation Reference Group	A group of patient representatives, members of the community, voluntary organisations, charities and local NHS staff which was set up to help create this consultation document.
Crisis	A sudden worsening of a mental health condition.
DCLL	Dementia and Complexity in Later Life – new service proposed by Norfolk & Suffolk NHS Foundation Trust.
Dementia	A syndrome (a group of related symptoms) that is associated with an on-going decline of the brain and its abilities.
DIST	Dementia Intensive Support Teams are community based teams supporting people with a dementia diagnosis and their family carers in their own homes and the community.
Foundation Trust	Foundation Trusts have greater financial freedom than other NHS organisations. Local people, patients and staff can become members and governors and hold the Trust to account for its performance.
GP (General Practitioner)	Your local family doctor.
Guidelines and Protocols	Statements, procedures or precise plans which help to determine a course of action. When shared, they ensure that all services follow the same procedures.

Healthcare	The diagnosis, treatment and prevention of disease, illness, injury and other physical and mental impairments. Healthcare is delivered in Primary Care, secondary care (local hospitals) and tertiary care (specialist services).
Health Overview and Scrutiny Committee (HOSC)	Health Overview and Scrutiny Committees carry out in-depth reviews of particular health issues of relevance to local people.
Inequalities	Differences in health between different groups of people.
Inpatients	Patients who need overnight stays for medical care.
Integrated Services	Integrated services bring different health and social care teams together, according to a patient's needs, to make sure they receive a full package of treatment to help them recover.
One-Stop-Shop	One place where a patient can access a range of health, social care and community services and advice.
NSFT	Norfolk & Suffolk NHS Foundation Trust – the NHS organisation which provides mental health services to patients in West Norfolk.
Primary Care	Primary care refers to services provided by GP practices, dentists, pharmacies and high street opticians.
Rehabilitation	A treatment or treatments designed to help the process of recovery from injury, illness or disease, to as normal a condition as possible.
Service User	People who use health and social care services, or who are potential users of health and social care services.
Social Care	A wide range of services provided by local authorities and the independent sector to people either in their own homes or in a care home or day centre. Services also include help with washing, dressing and home-help.
Stakeholders	Organisations and individuals with an interest in the activities of the local NHS.
Step-down beds	Step down beds refers to a facility where people who are medically well enough to be discharged from hospital but are not ready to return to their former home or level of independence, can be cared for.
TSS	Trust Service Strategy – the document that sets out Norfolk & Suffolk NHS Foundation Trust's vision for providing services in Norfolk and Suffolk throughout 2015-2016.

ISSUES ARISING FROM THE WORKSTREAMS

(June–August 2013)

1 IDENTIFICATION AND DIAGNOSIS ISSUES

- 1.1** The key role of GPs as the usual ‘first port of call’ for identifying those with dementia and securing the diagnosis was confirmed. However other professionals, including Hospital Doctors, who see individuals elsewhere in the health care system and identify their dementia, have a role to play in ensuring that the necessary steps are taken to secure diagnosis. It was identified that Addenbrooke’s Hospital in Cambridge has a particular role as people attend there for scans.
- 1.2** Emphasis was made of the importance of all professionals listening to carers and relatives (while not ignoring the patient) when individuals are being identified and of explaining to the individual and the carers what the diagnosis means. Professionals need to avoid taking patients statements at face value as they may seek to avoid diagnosis. Diagnosis at the right time rather than early was recommended; the need is that it takes place when an individual has sufficient ‘cognition’ to make plans for their future. The need for professionals to listen to other health and social care professionals was also a key message.
- 1.3** Individuals who may have dementia can have a fear of diagnosis believing it will automatically mean that they have to go and live ‘in a home’. They are affected by the attitudes to dementia of the wider community in which they live. As a result they can sometimes strive very effectively to avoid diagnosis and seek to beat the system.
- 1.4** The diagnosis rate for dementia in West Norfolk is the second lowest in England while the Clinical Commissioning Group area has the second highest number of people over 65 years of age and so the potential for a higher rate of dementia than elsewhere. The scepticism among GPs that if they seek a diagnosis for dementia for their patient, there is either effective medication to alleviate the condition or available services to help and support them may explain why the diagnosis rate is low. It may also explain why the ‘Commissioning for Quality and Innovation’ (CQUIN) enabling everyone over 75 years of age admitted to the Queen Elizabeth Hospital (QEH) to be assessed for dementia has made no difference to the diagnosis rate.

GPs need reassurance that there is more support available than just medication for their patients who are diagnosed with dementia. The support that is received from the Alzheimer’s Society for all types of dementia will repeatedly be mentioned in this document. Two GPs have met members of the Psychiatry and Neurology teams from NSFT and QEH to agree a memory test for GPs to use which will be recognised throughout the health system. Hopefully this will help to reduce the length of time it takes for a diagnosis to be made. All referrals for diagnosis are now sent to NSFT’s Access and Assessment Team (AAT) and feedback from them about each individual referred is important.

2 INFORMATION ISSUES

- 2.1** Carers identified NSFT and the Alzheimer’s Society as the key sources of information for those with dementia and their Carers. The booklet ‘Are you looking after someone’ is seen as essential as are the Carer Support Sessions run by NFST. There was concern that the Sessions had been reduced in content in recent times and in particular that the Alzheimer’s Society was no longer invited to

participate. At the end of the sessions, carers can feel that support to them has ceased. Those with dementia and their carers need to understand what services are available both from NSFT and Voluntary organisations and to know how to contact them. It was noted that many carers are not accessing services and cannot find out to whom they should be making a referral.

All those providing care need to be aware of who else is providing care as a lack of such knowledge often plays a part in care breakdown. The possibility of using care packs in people homes (??) to share information between those involved in care was discussed but the restrictions placed on sharing personal data may act as a constraint.

2.2 It is not just Carers who are at an apparent loss as to whom they should contact. Within the QEH there seems to be a lack of awareness of the Mental Health Liaison Team and the help it can give. GPs appear to lack confidence in what services are available and what constitutes an appropriate referral and re-referral. The training of GPs and Paramedics on the needs of those with dementia is required and there needs to be an improvement in communications between GPs and Carers where understanding is clouded by the use of medical language. There was concern that given the significance of the Dementia Advisors of the Alzheimer's Society in the lives of Carers, they are not receiving referrals in the numbers that they should. A database of services is under discussion on an East of England basis.

2.3 Good Communication about dementia is very important. On the wider front there is a need to educate the general community that social care for dementia is not just about 'going into a home'. However for Carers the introduction of Personal Budgets for Social Care has appeared problematic with inconsistency of knowledge and some confusion as well as a lack of help in completing forms and a difficulty in understanding the official language used. Amongst Carers there seems to be an insufficient awareness of the Carers Helpline.

Where care is needed, there is potential for better communication with care providers. Where that care is going to be in a home, the Alzheimer's Society has a factsheet to help in its selection.

2.4 There is work at the moment to try and coordinate online information and also the Norfolk and Suffolk Dementia Alliance have an education portal called 'Learning Environment'. The potential of GP Surgeries, Libraries, Pharmacies, Optometrists, Dentists, Care homes and Parish Councils for disseminating information and for publicity campaigns was discussed, as well as giving people information early while still at school. A recent innovation is the 'human library' and this may have potential on the subject of dementia.

3 CARE SUPPORT (MAINTENANCE IN ENVIRONMENT)

3.1 Research has shown that during a stay in an Acute hospital, each day as an inpatient there is a functional decline of 10% in the health of a person with dementia from the day of admission. This is something of which Hospital Staff need to be aware. They also need to have an understanding of the impact on someone with dementia that the loss of their daily routine can have, giving rise to other things such as a loss of continence. Wherever someone with dementia lives there is a need for a good hand over on any change of carer.

3.2 A common theme from the work streams was the importance of the Alzheimer's Society and of the Society's Support Manager and Advisors in King's Lynn. Contact with them comes through the community team of NSFT, self-referral, carer/family member and from Addenbrookes. The provision of support through phone availability, one to one meetings and through the dementia cafes is highly valued; carers and relatives need support quickly and easily. They are able to assist

carers who feel lost when the person they care for is discharged from NSFT to the care of GP and the information they are given is not clear cut. The funding for their work does not seem to be secure.

- 3.3** NSFT has recently decided to undertake a Radical Redesign of their services based on an expectation that the NHS nationally will require a 20% Cost Improvement Programme over the next four years. The resultant changes in their services for people with dementia have been implemented in West Norfolk over the past six months as part of NSFT's Trust Service Strategy. All referrals now go through NSFT's AAT. A Dementia and Care in Later Life (DCLL) structure has been established. The DCLL will have a community team and Dementia Intensive Support Team (DIST) with fluid interaction accessed through the AAT. DIST will be a team of three people on duty on a shift, seven days a week covering West Norfolk and other areas NSFT have decided to make part of their West locality. DIST will be a community service also working with QEH, predominantly over falls.

West Norfolk DIST will be able to refer patients for low level care into currently two NSFT commissioned beds in a select care home with West Norfolk for lower complexity dementia cares. They will be able to refer through the DIST in Central Norfolk those with challenging behaviour to Blickling Ward in Norwich. Concern was expressed in the work streams that Blickling Ward is inaccessible to patients, carers and families in West Norfolk.

With services as they have been working, carers have been concerned over the length of wait between when a carer finds themselves with a dementia person crisis and getting help. Also there is concern over the speed with which people with dementia re-enter into receiving services when they have been out of the system.

- 3.4** Carers value support from Social Care but length of time and timeliness of Carer's Assessments, as well as its occurrence, style and value, is an issue for them. There is also a backlog in Social Services Carers packs being 'uploaded' onto County Council information technology systems. It is acknowledged that the Social Services Elderly Support team accords equal significance to users and carers. There is little support for those who self-fund their care although they have access to 'Care Aware'. For those who fail to meet County Council criteria and cannot afford to self-fund there is a real problem. Carers value access to respite for the person with dementia in their care for the break that keeps them going, but respite care is complex to secure and an apparent inflexibility. The Crossroads sitter service, day centre and day care are valued but have been subjected to budget cuts. The 'Short Notice, Short Break Service' exists but is not adequately used, however it has been subject to a change of criteria.

The Aids and appliances are a good resource but can be slow while there is no common understanding of how to access aids from the British Red Cross.

- 3.5** The Joint Assessment Team provides support to vulnerable people and provides intensive support and appropriate care and is a valued resource for carers and people with dementia. The East of England CQUIN is a significant innovation for dementia care. However the experience of carers who need to use the Speech Therapy and Occupational Therapy is that there is a very slow response time. The work streams were interested in the potential of 'Dementia Champions' and 'Dementia Friends' and of Dementia Coaches particularly in care homes.

4 END OF LIFE

- 4.1** People with dementia have the same access to end of life services as those without. There are a range of Palliative Care Services including those at QEH led by Dr Blackburn – Shouldham Ward, the Macmillan Centre and the Hospital and Community Macmillan Teams; Day Services at Tapping House and Primary and Community Services provided by GPs and Community Nurses. Since December 2012 a West Norfolk Clinical Commissioning Group commissioned Hospice at Home service has been provided as a joint venture between Norfolk Community Health and Care, Norfolk Hospice-Tapping House and Marie Curie with two full time nurses and three part-time healthcare assistants, with Norfolk Hospice funding the service to achieve seven days per week coverage. The criteria for patients accessing this service are that they must be in their last 6-8 weeks of life. For patients with dementia, professionals are less able to identify when a patient is entering the last 6-8 weeks.
- 4.2** After diagnosis for dementia, end of life may be thirteen years or more in the future and so to discuss this sensitive issue with carers and people with dementia at the time of diagnosis is not straightforward. The focus at diagnosis is on the positive aspects of life ahead. There is then a gap after which discussion may be more appropriate but will have to be handled very sensitively. There is also an issue of those with dementia who are independent, with no carer and in some cases may self-neglect which complicates professionals from correctly identifying the severity of their symptoms. The work stream was recommended to consider the Peterborough end of life scheme.

Extracts of data from 3 qualitative evaluation methods

1. Indicative feedback from DCLL acute pathway qualitative evaluation report, July 2014

In line with the NSFT recent service reconfiguration, an in-depth qualitative study has been commenced to evaluate the service model so far. Service users and carers who have either been admitted to one of the wards at the Julian Hospital, or admitted to one of the alternative to admission beds (ATA) at a local care home, or have been receiving a service from the dementia intensive support team (DIST) have been interviewed and notes taken on their experiences.

This evaluation is a work in progress and further data will become available as time progresses and more service users are seen. The collection of data has been somewhat problematic due to the complexities around the service users being part of a mental health service. Although the data has been collected at random, there have been some people who have not been able to be included, for example, if the service user has since passed away, if they are deemed to lack capacity to consent and there is no carer, or if their current mental health is in a state of crisis and it is felt that to be conducting the interview at this time would lack sensitivity. All people interviewed have had the same set of questions asked of them, with the wording altered very slightly depending on which part of the service they have been part of.

Julian ward admission

One person was interviewed regarding their family members admission to Sandringham ward. The family member reported a very positive experience of the liaison consultant who was said to be 'amazing' and who arranged the admission. The reason for the admission and the process itself was fully explained to them and they were happy with this. They reported the care on the ward to be good, the staff were 'brilliant' and the place was 'awesome'. They felt that the staff working on the ward were responsible for getting their family member better again. They described how they were flexible with visiting hours, to fit in with the travel from Kings Lynn. Prior to the discharge process, they were told it would be planned and were aware of the arrangements and were happy with how this was done.

AtA bed admissions – qualitative evaluation

Of the 4 family members interviewed, the following themes have been found:

The staff at the care home are consistently reported to be 'friendly', 'lovely' 'helpful' and 'fantastic'. It was reported that 'nothing is too much trouble' for the staff there. The manager was reported to be 'brilliant'. Families liked that they could visit when they liked and always felt welcomed.

There was consistent praise for the fact that it is a care home and not a hospital, with families saying it was 'better than a hospital' environment and that they felt 'relief' when they found it wasn't a hospital.

However there were also numerous comments that the environment seems 'dated', 'confined', 'drab' and 'dirty'. There were consistent comments around the care, with families describing that they 'could not fault the care' and that the care was 'good'. There was also consistent praise for staff from the DIST, as being good at keeping families informed of what was happening.

2. DIST survey evaluation report

During the period of 17th August 2013 – 16th August 2014, 23 questionnaires were returned, and included in this evaluation. Questionnaires asked multiple choice questions, and also asked for suggestions for improvement and comments about the best part of the service. Responses for each multiple choice question are displayed as percentages.

Overall, the majority of users of the DIST service were happy with the care they received. They generally felt their views were taken into account and importantly 100% felt they had been treated with respect and dignity at all times. 78% rated as 10/10 that they would recommend this service to a friend or family member that requires assistance from a mental health service. All service users rated this as 8-10/10. Service users also provided positive comments, and particularly liked that support considered carers in addition to the individual. Some suggestions were made by service users, including improved communication and prompter responses from medical staff. Positive feedback was also received from professionals working with the team. However, only 23 questionnaires were returned and completed in the evaluation and so it should be considered that the report only represents the views of 23 service users.

3. Indicative feedback from 'your say your service' (October to December 2014)

" We have had and are receiving wonderful care, kindness and support. Without the help of the team life was very difficult. We can't thank them enough for their patience, kindness and caring. It is so reassuring to know there is always someone we can turn to for help. We are very grateful to such a wonderful team. A very big thank-you."

"Fantastic service, so caring and understanding. Helped me and my wife so much."

"I am pleased with everything that was discussed and provided today. Thank you."

"The home treatment team helped me to get back on my feet after a month long spent with depression. Have suffered from chronic depression on and off for many years. Being treated at home seems on the whole a better alternative to being in hospital although I was sceptical at first."