

Dementia Services for Rutland People

10 key messages from the people of Rutland



May 2016

INTRODUCTION

Caring well for those with dementia is a high national, international and local priority and especially so in Rutland where numbers of elderly are rising so rapidly.

Locally we have many excellent services but there are also gaps. We wanted to hear users' and carers' experiences but this report also draws on the valuable insight of about 300 carers, professionals, voluntary organisations and planners.

Healthwatch Rutland looked at services with the people who both use and those who provide them and describe here what they said and we continue to listen to people's experiences.

This interim report was prepared for commissioners who are developing new services including the Better Care Together Programme. We hope it will be helpful.

It is available on our website (www.healthwatchrutland.co.uk) or as a hard copy by contacting Healthwatch Rutland (01572 720381 or info@healthwatchrutland.co.uk)

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10 KEY MESSAGES

On this page we have inserted one key message for each of ten stages of dementia care for Rutland people. The remainder of this interim report describes the comments and evidence that lie behind each of these messages.

Binding all ten messages together is the theme of the whole journey needing to be joined up into a coherent whole.

1.DECIDING TO SEEK A DIAGNOSIS - More could be done by organisations working together across the whole community to raise awareness of memory loss in Rutland and dispel the stigma and fear of " dementia".

2.GOING TO THE GP FOR HELP -GPs would welcome help to support families to come forward to seek a diagnosis. The Rutland diagnosis rate is still below target

3.GETTING A DIAGNOSIS -There is lack of clarity about the many routes people can take to obtain a diagnosis. The system feels slow, cumbersome and confusing to those in it.

4.GETTING TREATMENT-Those getting treatment also found the system confusing and fragmented.

5.INFORMATION -Getting the right information tailored to each stage is very important but does not happen.

6.SUPPORT AT HOME AFTER STARTING TREATMENT (Clinical & Social)
People feel that system of care coordinators is needed to help those less able to find their way around such a complex mix of statutory, voluntary and commercial services. Linking these services in a more cohesive way is now being addressed and is vital.

7.CARE HOMES & DOMICILIARY CARE -Relatives struggle to find residential and domiciliary care of suitable quality. They feel this shortage will get worse as demand rises and if new services are not provided.

8.SHORT BREAKS -Carers value respite care and short breaks but it can be stressful for all concerned. Carers would like more flexibility both in the packages on offer and financial arrangements.

9.HOSPITAL - Hospital admission is best minimised for those with dementia but remains the largest source of referral for diagnosis. Considerable improvements have been initiated with government funding in surrounding hospitals and need to be evaluated. People in Rutland attend many different hospitals and the problems of delayed and inappropriate discharges continue to bedevil us.

10.END OF LIFE -We will be looking at end of life care for *all* people and have not yet undertaken this critical work.

DEMENTIA - THE NATIONAL PICTURE

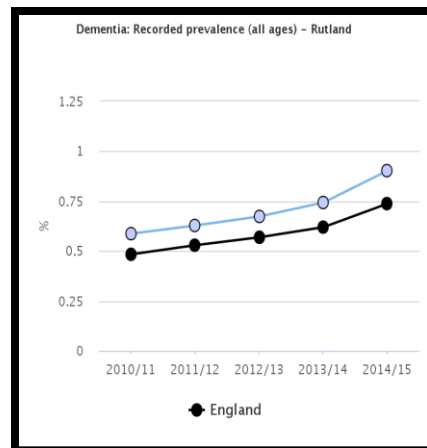
Incidence *

While dementia affects all ages, it is a syndrome more common among the elderly and will increase dramatically as the older population grows. There are estimated to be over 850,000 people with dementia in the UK. By 2040, the number affected is expected to double and the costs are likely to treble.

This is especially so in Rutland where, not only is the overall population expanding but the percentage of residents over 65 years is expected to rise to over 35% of the population by 2035. The numbers of those with dementia in Rutland is expected to more than double between now and 2030 from around 650 at present (Source JSNA update 2015).

Prevalence *

The all-age prevalence rate in Rutland is among the highest in the Region and higher than the English average (Source Public Health England 2016)



Cost to society and to families

The Alzheimer's Society has estimated the cost to the UK to be in excess of £26.3 billions per annum with just under half (equivalent to 150,000 years unpaid labour) being made up by carers. (That is enough to pay the energy bills of every household in the country.)

Even this huge contribution by carers is not keeping pace with demand. The Alzheimer's Society also estimates that 43% of carers do not currently get adequate support with East Midlands reporting one of the lowest levels of support to carers.

Dementia Policy There is a huge policy momentum nationally and internationally and including the personal backing of the Prime Minister to support all those affected and, if possible, find a cure. Work has started on preparing a revised dementia strategy for Leicester, Leicestershire and Rutland as part of the Better Care Together Programme

*Footnote

Incidence differs from prevalence. Prevalence is the proportion of cases in the population at a given time rather than rate of occurrence of new cases and is more a measure of the burden of the disease on society. Prevalence answers "How many people have this disease right now?" Incidence answers "How many people per year newly acquire this disease?"

1. DECIDING TO SEEK A DIAGNOSIS



More could be done by organisations working together across the whole community to raise awareness of memory loss in Rutland and dispel the stigma of "dementia".

Identification of dementia is notoriously difficult and compounded by determination on the part of many people to avoid recognising the tell-tale signs.

Fear by the public and the stigma of dementia is a *real* issue and pushes many families into denial preventing them from receiving help at an early stage.

Despite having many supportive communities across Rutland, people told us they would like to see a county where people find it more socially acceptable to talk about dementia and to seek help early. They welcomed the guidance offered to local authorities in LGA guidance "Dementia Friendly Communities" issued in August 2015.

Recommendations

1. Rutland County Council be supported through the Health and Well Being Board in creating an awareness raising alliance of agencies similar to that found in Norfolk. Public awareness can be increased via groups such as the Dementia Action Alliance.
2. Much could be achieved by resolving inconsistency of roles and using longer term contracts.
3. People are unsure where to go to seek information at this early stage and we recommend an organisation(s) be nominated and publicised as a local source of advice for families just starting to have concerns but who are not yet ready to consult the General Practitioner(GP). The Alzheimer's Society is a possible choice.
4. It would be helpful if the growing number of Dementia Champions in Rutland could be aware of each other and also for the wider Rutland community know it has access to them and who they are. They can play a valuable role in gathering patient and carer experience.
5. Schools should be dementia aware and able to support children in families living with dementia, some of whom may become carers.
6. The Clinical Commissioning Group(CCG) encourage all practices to participate in the extended scheme to both help break down stigma *and* increase early diagnosis rates which still are below the national target of 66% (source CCG)

2.GOING TO THE GP FOR HELP



GPs would welcome help to support families to come forward to seek a diagnosis. The Rutland diagnosis rate is still below target

Despite having heard that stigma slows people making contact with GPs, we were heartened to learn of national initiatives to support primary care surveillance via programmes such as '*GP enhanced specification*' together with a whole range of national resources available in "Dementia: 10 Key Steps to improving timely diagnosis".

Things GPs told us

We were also heartened by the commitment among Rutland GP practices. We met with Rutland General Practitioners, Consultant Psychiatrist and Specialist Dementia Nurse from the Evington Centre. Issues identified included:-

- Stigma - GPs also highlighted families not wanting to refer, or in denial.
- They felt that other workers who come into contact with people displaying symptoms also need to be aware of the condition eg pharmacists, chiropodists, hairdressers etc.
- There is much reliance on individual workers within hospitals identifying patients with dementia symptoms.
- There are IT gaps between different parts of the health service eg hospital discharge letters from hospitals sent to GPs are much quicker from UHL as it is electronic. Other hospitals are slower.
- Referral routes - It was noted that Leicestershire Partnership Trust receives the majority of its referrals from hospitals rather than GPs.
- There are transition issues as things move towards a diagnosis. This needs handling sensitively across the several organisations involved to avoid stress within the family.
- 10 minute GP slots are a barrier. They do not allow enough time to undertake an assessment. Diagnosis of dementia cannot be done in a day. Diagnosis has to be done on a continuum over time. Customer expectation therefore needs managing during this time.
- GPs worry about public perception by receiving £55 for every referral

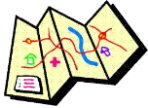
Conclusions

- Diagnosis rates in Rutland could still be better.
 - Both patients and clinicians said there was a need for a clearly described and joined up dementia referral and care *system*. It is fragmented.
 - GPs said they feel they are not fully aware of activities and services elsewhere which inhibits them from playing their part fully.
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Recommendations

1. **National guidance.** CCG Locality wide (ie Rutland, Melton and Harborough) implementation of the "10 Key Steps to improving early diagnosis".
2. **Being aware of early information about new services.** There is a need for partners to share information about the parts of the service they provide.
3. **Knowing about services - Care Coordinators.** GPs get limited information regarding services available which curtails where they can refer people to. Care coordinators would be greatly valued as a key link with GPs.
4. At an individual level and since this workshop was held, NHS England has published "*One person, One Team, One System*" under the leadership of Sir John Oldham. This report addresses the issue of coordination for the individual.
5. **Local Authority procured services** Alzheimer's Society do provide support through the Dementia Cafés etc but this is not always suitable for those individuals who live on their own and/or cannot attend support groups. GPs want more information regarding local authority and community services that will support them e.g. laminated sheet regarding key contacts and links to information.
6. **Sharing facilities.** At a basic level there is a memory clinic based at Rutland Memorial but we have heard from the Alzheimer's Society that they cannot join this clinic for want of space so consequently are not there to direct people to the information available.
7. **Rurality.** Oakham based services are a problem for people in the villages.
8. **Patient Participation Groups (PPGs).** It is recommended that Alzheimer's Society should be involved in PPG work.
9. **Other Pathways.** Given that the majority of referrals are currently initiated in hospital, we recommend that the East Leicestershire and Rutland Clinical Commissioning Group and Rutland County Council investigate whether pathways in Peterborough, Stamford and Kettering are effectively dovetailed.

3.GETTING A DIAGNOSIS & 4.GETTING TREATMENT



There is lack of clarity about the many routes people can take to obtain a diagnosis. The system feels slow, cumbersome and confusing to those in it. Those getting treatment also found the system confusing and fragmented.

What people told us about obtaining a diagnosis

We had feedback from a number of sessions about diagnosis and treatment. What is striking about people's comments and questions is their lack of clarity about the system they have been through. It indicates that the system itself is not clear.

We posed them six questions about diagnosis and treatment.

1. Who will make the diagnosis?
2. What treatment might be appropriate?
3. How long would you expect a referral to take? (GP to Consultant)
4. Where would support during this waiting time come from?
5. Who would you expect to be involved in this consultation?
6. What would you need following the diagnosis?

There were two themes from what people told us in reply.

1. The referral process is both cumbersome and confusing. People want it to be sleeker, faster and take account of patients moving across borders. People want written and other guidance about the pathway they are following and the stage they are at.
2. Post diagnosis, families feel a need from time to time for both information and a system navigator or care coordinator. This was not identified as a continuous need but spasmodic as families encountered problems

Recommendations

1. Agree a clear united clinical and social care pathway that integrates with neighbouring pathways (Peterborough, Stamford and Kettering) and which is written up clearly and made widely available to patients, carers and staff.
2. While people are waiting for a diagnosis there is a need for them to acquire information. Most people said they prefer to receive information via face to face contact.
3. There should be a debate between carers and health /social care commissioners/providers to agree a model of coordination support for individual families.

5. INFORMATION



Getting the right information tailored to each stage of care is very important but does not happen.

There are two types of information service available to Rutland people and organisations tend to be somewhere along the spectrum

1. Sign posters to information sources
2. Direct providers of information.

There is no shortage of services giving out information but what emerged is a picture of a complex network of organisations trying to work together but not always coming through as a joined up resource to those on the receiving end.

Things people told us about these services

Integration Patients and carers said that they would like information services to be integrated, quality assured and appropriate to the stage of the pathway. Many signposting systems rely on the use of the internet but a number of people in Rutland do not own or use a computer so they need to be able to speak to an advisor on a 1:1 basis which is the preferred mode for many.

Information was a constant topic which came up at many events and has different aspects. We asked people the following questions:-

- **What information might people need?** People described a *range of information* they wanted. This included:- pre diagnosis; service options; future care funding; other financial and legal issues such as Lasting Power of Attorney; benefits; carer support; respite options; information explaining how the diagnosis will affect someone and their family; what might change; what to expect; next steps to take.
Post diagnosis - they said that the professional giving advice needs to consider the period of acceptance of the diagnosis before overwhelming the individual and carers with information.
Issues included what is available to help the carer care; information packs; verbal and written advice. Topics included life expectancy, will other family members get dementia, medication for condition etc.
- **How would people find out?** People regarded the GP as pivotal. Other sources cited are health and social care professionals, voluntary sector sources (including CAB signposting service; Community Agents /First Contact; Alzheimer Society; Age UK; Library; Internet; Memory Clinic; Supermarkets & other busy outlets; market stalls; free newspaper if there is one; Memory Advisor or main Care Coordinator; organisations that have buses that visit villages such as Spire; agencies signposting to each other; and churches).

- **Who might be able to help?** As above. Health and social care professionals, generally the GP, were consulted first. ("As professionals it is their duty"). Others included:- voluntary sector; Dementia Friends awareness sessions; Coordinator; Police; Community Mental Health Teams; Carer Support Groups; Lifeline services/providers; other care providers. People discussed having a vulnerable adults register and how ethical/practical it was.
- **What about paid carers?** Private homecare providers were felt to be varying in quality of service from excellent to poor. There is an issue of regulation. It was noted that contracted agencies are monitored by Rutland County Council Contracts and Care Quality Commission while other services are not.

People felt they could have more control over Personal Budget monies if using a Direct Payment which enables them to use non contracted homecare agencies.

It was felt that re-ablement services should be considered before having to use homecare.

- **People living alone** It was felt that no one is monitoring deterioration among people with dementia who live alone. There are concerns about the consequences of debt, not taking medication, neglect, isolation/depression etc. Police might be the first professionals to come across the person if 'wandering' and many of this group do not have a diagnosis.

When the person lives alone it was felt to put more pressure on informal care networks such as neighbours. Some people are without positive networks around them eg. friends and family. Without preventative support, they are liable to move more quickly into social or healthcare services. There is also the possibility of abuse.

Recommendations

1. Patients and carers would like information services to be both integrated, quality assured and organized into bite sized chunks appropriate to each stage.
2. Many signposting systems rely on the use of the internet but many people in Rutland do not own or use a computer so need to be able to speak to an advisor on a 1:1 basis.
3. There needs to be an overall review of the outlets where good information can be had.
4. Specific arrangements need to be planned for the information needs of people who live alone.
5. People welcome the opportunity to be involved in research and should be given the opportunity.

6.SUPPORT AT HOME AFTER STARTING TREATMENT (Clinical & Social Support)



People feel that system of care coordinators is needed to help those less able to find their way around such a complex mix of statutory, voluntary and commercial support services. The task of linking these services in a more cohesive way is now being addressed and is vital.

Things people told us about non clinical support services at home

In April 2015 we consulted domiciliary care and housing support agencies. We also attended the Winter Health and Wellbeing event and discussed the services provided by Care & Repair, Alzheimer's Society, CAB, Spire, Rutland County Council Adult Social Care, Fire Service, Voluntary Action Rutland Car scheme, Rutland County Council Housing, Falls Project, Police, Specsavers, and Energy Action.

- **Information** After diagnosis is made and the patient or family begins to comprehend the enormity of the diagnosis, most people said that this was a critical time when they needed information. Many felt that a review of financial and legal affairs should be undertaken at that stage.
- **Financial and legal affairs** include appointing a Lasting Power of Attorney (LPA) for financial affairs and in relation to health and welfare. (The alternative is an Advanced Decision/Statement in relation to health and welfare choices). Financial and legal also include writing a will, identifying entitlement to benefits etc. e.g. reduced Council Tax, carers and attendance payments etc.
- **Health and Social Care needs assessment.** It was felt this needs to be publicised more as well as direct payments and personal care budgets.
- **Support to live as normal a life as possible** for as long as possible was felt to be very important, and the information and support to achieve this is critical. Keeping people engaged, proactive and within the community is vital. We held a separate workshop on **technological support** where people gave their views.
- **Community awareness** People living with dementia need to feel supported within their community. It was felt more should be done to educate the wider community as to what it is like to live with dementia.
- **Voluntary Sector** It was felt that a dementia-aware voluntary sector is needed to support those both using and independent of the social care system.
- **Risk avoidance** The risks and benefits of establishing a data base for vulnerable people were discussed. It was felt that the *Keep Safe* card should be integrated with the post assessment process and made routinely available on diagnosis.
- **Other issues raised** Needs of people in border villages; Social Care Assessment (Individual and Carer); Dentistry where surgeries do not have suitable facilities. Families would like domiciliary visits although they did appreciate the problems of the dentist not having a chair to do any work required. Continuing Healthcare (CHC) assessment delays and personal and direct payment budgets.

Recommendations

Overall the feedback from patients and carers does not provide assurance that that the support system after diagnosis is as integrated as it should be.

1. **Dementia Advisor (specialist) role** is regarded as essential to support individuals immediately following diagnosis passing on to other coordinators from other organisations later. There needs to be a mechanism for GPs and other practitioners notifying advisors of a new diagnosis.
2. **People living alone.** Support is complicated and not as coordinated as it could be. A person living alone could get 4 visits from 4 different care workers within 6 hours. People are usually left in bed until carers arrive e.g. breakfast can be between 7 and 11am so there might be no visit for a long period of time. Assistive technology has a place but for many living a lone can be unsafe if it is the sole means of support.
3. **Care Home admission to hospital avoidance.** Work with care homes is crucial to support admission avoidance. Care home staff need training. It is not clear to care homes how this training should be funded.
4. **Lasting power of attorney** needs to be earlier in the pathway at the information point or under identification of dementia. It could also be put within planning for retirement information as part of a service directory (NB The issue of early preparation of power of attorney has been echoed strongly in our discussions with carers).

A list of those members of the legal profession who would be willing to provide this service locally would be very helpful.

7.CARE HOMES & DOMICILIARY CARE



Relatives struggle to find residential and domiciliary care of suitable quality. They feel this shortage will get worse if new services are not provided.

Things people told us about care homes & domiciliary care

We were struck by the story told by one lady whose husband had been ejected from several homes as he became increasingly violent. She eventually found a nice home in Leicester run by a caring Indian family. Sadly her husband could not adjust to the cultural differences so she was again on the road searching for a new home and making 50 mile round trips by bus each day to visit him.

We heard many similar tales and the key message was not about the current provision of services but about the *lack* of services in Rutland.

We did not speak directly to residents of care homes. We did, however, speak to carers with relatives either in care homes or receiving domiciliary care as well as care home providers.

What providers said about care home services in Rutland

The good & bad We invited all the care homes in Rutland to a workshop in December 2014 and held discussions assessing the good and not so good and making recommendations for improvement. The positives and negatives are listed below.

Positives	Negatives
GP Plan	Out of hours services are troublesome
Access to training locally	Backfill is a difficulty at times
LPT In-reach	Can be 6-8 weeks referral wait
Community engaged with activities	
Young people becoming more dementia aware	
Dementia friends – talking about WWII	
Local schools involved at the care homes	
'Remember Me' (Alzheimer's Society), Life Story on doors. Staff at CL have the same on office doors. Memory boxes also used	CQC sometimes struggle with some of these ideas due to concerns around data protection.
Skype is very useful for keeping long distance family relationships going	Depends on location of home as some don't receive a strong enough connection/signal
Assistive Living Technology (ALT)	
Relationship with local authority	
	Hospital – losing forms, patient has a long wait for transport, often after 6pm and sometimes very late. Often inappropriately or inadequately dressed, no hydration, no blankets. Post codes can cause problems for continuation of care. Medication is often mislaid, not returned

	Biggest cause of alerts are pressure sores and lack of hydration
Falls -Tixover uses " Footsteps" (a recording chart)	Falls Team will not take patients with dementia
Care Plans GPs at Uppingham, Wansford,(Tixover) Oakham and Empingham (Oak House) are proactive with care plans	
	Death - Coroners protocols for anyone dying in care are the same as anyone dying in custody and leads to a mandatory inquest. This can be distressing.
Activities & Outside trips As an example of good practice,-- Oak House can accommodate residents who want to help in the kitchen and also has Oakham School Pupils and volunteers to visit.	More resources are needed to support such activities

Transport issues - Care Homes described the interface with Ambulance Service (EMAS) & Arriva as cause for concern. Care home staff expressed specific concern about falls. The combination of 111 and EMAS protocols makes admission almost inevitable with all the consequences hospital admission can bring. There is no EMAS falls team covering Rutland and the Rutland County Council Falls Team will not take Dementia. Late return after hospital admission causes distress and disorientation.

Assistive technology Homes and GPs would like more information on what is available.

Care Home Training .Providing care and residential homes staff with dementia training is vital (a view shared by Care Home staff) especially where aggressive behaviour is involved).

Recommendations

1. **Availability** . Increasing the availability and choice of care homes taking dementia patients in Rutland was felt to be essential.
2. **Quality Assurance** Care Quality Commission reports on local dementia Care Homes can help families with forward planning but they are often delayed. People would also welcome a list of approved care support agencies.
3. **Falls** Undertake specific project with EMAS/ RCC to reduce falls.
4. **Arriva Transport** Resolve problem of late return of patients from hospital.
5. **Training** Resolve funding of training for homes staff
6. **Support Care homes** Create a learning set on dementia for homes. They would welcome this resource.
7. **Safeguarding** Homes should know how to raise Safeguarding Alerts and Safeguarding generally needs to be understood by staff.
8. **Care Plans** Care plans need to be pro-active and reflect the wishes of the patient. Admission to hospital should be seen as a last resort.
9. **LPT** More 'in-reach' support from Leicestershire Partnership Trust is needed.
- 10 **Homes** Homes would welcome a means of obtaining informal GP advice.
- 11 **.Support for Carers** More support needed for Carers and relatives especially in understanding how dementia may affect a person e.g. weight changes

8.SHORT BREAKS



Carers value respite care and short breaks but it can be stressful for all concerned. Carers would like more flexibility both in the packages on offer and financial arrangements.

Things people told us about these services

We held two workshops in 2014 and 2015 to look at respite care.

- **Overall availability of respite care in Rutland.** Carers felt that choice and availability are very limited in Rutland. Several said they would really like to see a brochure of possibilities coupled with reviews from other carers who had used the services.
 - **Provision** In general, carers appeared to prefer non institutional provision because if their relative went into a care home for respite, their routine could be disrupted and it took a long time to get them back on an even keel.
 - **Entitlement and eligibility (including Carer support)**
 - o Carer's knowledge of their entitlement to respite care; the process for accessing support; and the quality of respite care was not always evident. Nor are they aware of the support that is available to them personally as carers.
 - o The evaluation process for respite was questioned as effective.
 - o The pivotal role of the GP in signposting carers to services and their entitlements was identified. Uppingham and Empingham practices were both praised for this.
 - o Fear of asking Social Services for help. There is still stigma attached to this. There needs to be a comprehensive but *independent* signposting system.
 - **Periods of respite care** There was a great desire on the part of carers to have flexibility in choosing the period of respite to suit their circumstances but felt that the system was regulated by contract requirements which tended to give a rigid choice of lengths of stay. This could possibly be addressed by direct payments but ran into the problem of the carer having to find providers.
 - **Types of respite care** There was also a desire for a wider range of options eg different locations ie care home or at home or large or small home.
 - **Emergency respite care** Carers felt that the system was not always geared to support them when disaster struck. There was discussion as to whether this was a real provision problem or rather one of communication in ensuring the carer knew what to do in an emergency to access support.
 - **Care Homes** The problem of care homes only offering one or two week blocks was felt to be too rigid.
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- **The individual** The " *This is me*" focus on the individual was strongly recommended as well as matching paid carers activities and outings to the individual person's interests eg. gardening.
- **Financial support** Carers would welcome clear guidance on what financial support is available.
- **Day Care** One couple described how outings often provided the change that gave them respite. They appreciated one-on-one outings eg sessions at day centres- memory cafe - Rutland Reminders etc but regretted that these facilities were getting much more difficult to find as cuts took their toll on services.
- **Other models of provision.** Other models of day care (Droitwich and Holland and Peterborough) were also described.

Recommendations

1. There should be a comprehensive guide to respite care for Rutland residents (publicly funded as well as self funding) coupled with a guide to financial support available.
2. It would be helpful if ' pick and mix' options could be made available within the RCC contract framework to allow carers flexibility over location and type of care they could chose.
3. Many families use day care as a form of respite care and these facilities should be included in the guides. Planners should be aware of the key role such facilities played in helping keep people at home when considering future cuts.

9.HOSPITAL



Hospital admission is best minimised for those with dementia but remains the largest source of referral for diagnosis. Considerable improvements have been initiated with government funding in our surrounding hospitals and these need to be evaluated. People in Rutland attend many different hospitals and the problems of delayed and inappropriate discharge continue to bedevil us.

This section is still 'Work in Progress' because our three most used district hospitals (Peterborough and Stamford, University Hospitals of Leicester and Kettering General) have been implementing enhanced services funded by the Prime Minister's Challenge on Dementia. After implementation has bedded in, we hope to ask patients who have experienced these new regimes how they found them.

Access to hospitals is a complex business as a result of Rutland being small.

- People who live in Rutland can be receiving services for a number of conditions from the acute hospitals in Rutland, Peterborough and Stamford, Cambridge, Kettering, Grantham and Nottingham as well as Leicester and Leicestershire
- Some Rutland residents have GPs in other counties so are not covered by the East Leicestershire and Rutland CCG commissioning plans.
- Pathways in Rutland have been developed with a Leicester focus. New relationships have to be developed with other hospitals.

A workshop was held in April 2015 to discuss the new dementia strategy at UHL and a map of the new services available in UHL is available. Similar work needs to be done on all other hospitals serving Rutland. Discussions are underway with UHL to find a way of testing consumer opinion about the new strategy.

What people have told us about hospital services

People described a variety of routes into hospitals

- **Accident and Emergency** People were taken there either because they were wandering and confused and needed a place of safety or because they were admitted as a result of an emergency admission eg a fall. Admission via A & E could be either through the Ambulance route (initiated by Police, Social Workers, GPs, family etc) or via the GP and the bed bureau.
- **General wards** via a cold admission for another condition. Admissions also go into **private sector hospitals** either via the NHS or as self funded admissions.
- **Formal referral into the Dementia Service.** There was felt to be a need for a clearer gateway into the secondary service via the GP. Referral patterns are very mixed.
- Acute admissions via the **mental health team** were described as difficult.

We asked what problems might arise?

- **Police calling 999 ambulance**
The police described how they were often called (mainly at night) when people were found wandering and could not be identified. If the person could not be identified the police would call 999 and the paramedic would check the person over before dispatch to hospital.

The police use the 2005 Mental Incapacity Act when necessary. This has been known to involve the use of handcuffs.

- **Social Work Crisis Response Team**

This scheme was being piloted as part of the reablement strand of the Better Care Together Fund. It aimed to provide 24 hour service and, where admission via A & E was not warranted, aimed to bring patients back from A & E and support them for up to 72 hours at Rutland Memorial Hospital until next steps could be determined.

There was felt to be a need to clarify relationship for the public between Crisis Response Team and Social Work Emergency Team (see below)

- **Social Work Emergency Team**

An out of hours crisis would generate a risk assessment (in conjunction with a neighbour or via police) The decision might be to keep the patient at home but if there was risk an ambulance would be called (The team has a good information sharing agreement with Spire Homes which helps).

- **111 & Out of hours service**

Out of hours did come out to visit but problems were reported.

- **GP admission**

For emergency admission this could be a slow process to get a GP to come which involved supporting the patient somewhere often for long periods (The police said if they were involved they could not hang around so usually found a neighbour or relative to take the patient in while waiting).

For cold admission, this followed the normal process but there was often little flagging up that dementia was also suspected or had been diagnosed.

- **Care Homes**

Care homes have been enrolled by the Council in the Better Care Fund admissions avoidance scheme (the aim is to reduce admissions by 2%). Each home has a statement to call the GP or 111 (NB GPs are fined for non-compliance. Homes appear to be complying and the directive seems to be helping where the staff are inexperienced).

- **Admissions via Mental Health Team**

It was reported that even in a crisis they refer back to the GP for formal referral back to CPN service and will not take crisis referrals. If the GP feels the patient is not acute without a recent visit the social worker is left to deal with it. It has been known to get the patient sectioned as the only way of securing admission.

- **Discharge Process and follow up**

- Attendees reported issues of dementia awareness in the discharge process. They felt it could be more formally included in the hospital discharge process. It was also felt that carers should be more closely involved in the discharge plan to double check patients' perception of the level of support that existed and the patient's ability to cope eg self medicating.
- REACH was described as a 4-6 week service with a 1/2 week safety net. but people described problems with assessment of people being assessed as "moderate" when they were actually "severe". People were, consequently falling through the net. Problem of re referral when circumstances change.
- If patient is referred back to GP to go to a memory clinic, these are good but only available in Leicester

Recommendations

1. Test how effective new nationally funded internal hospital dementia pathways are in addressing issues identified by asking users and carers about their experiences.
2. New approaches could help resolve many of the issues eg:-
 - Make referral routes clearer including gateway role of GP.
 - Adopt John's Campaign which asks that carers of people with dementia have the same rights as parents of sick children to accompany them in hospital and be their voice.
 - Use Card Safe system to help identify *lost* patients
 - Awareness training among general staff in hospital (and especially in private sector hospitals) is patchy.
 - Improve the bureaucratic emergency admission procedures with the Mental Health Team
 - Improve discharge procedures to include consideration of dementia as well as physical conditions being primarily treated
 - Publicise the relationship between the Crisis service and REACH
 - Increase availability of memory clinics to places other than Leicester.
 - Extend LRI elderly Team to Orthopaedic wards.
 - Formally include consideration of dementia in the discharge process
 - Include Carers in the discharge process

10. END OF LIFE



We will be looking at end of life care for *all* people and have not yet undertaken this critical work

It is vital that not only dementia patients but all patients should have a good end and we will be joining with other Healthwatch to assess how sensitively and appropriately these services are delivered.

ACKNOWLEDGEMENTS

This report is an interim report which has involved a great deal of work by a large number of people and provides the first Rutland wide picture of dementia care from a user and carer perspective. The process of listening will continue.

People with dementia, carers, professionals, commissioners and people from many walks of life outside health and social care have given a great of time and energy in putting the spotlight on dementia services and describing what users and carers think about services while going through what can be a difficult journey.

The project would not have happened but for the dedication of Margaret Demaine, and the members of the Healthwatch Rutland Dementia Task Group.

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Published & Printed -May 2016

Healthwatch Rutland is operated by Healthwatch Rutland Community Interest Company
It is a not-for-profit organisation established to serve the community of Rutland (No. 08943486)