Rotherham Dementia Action Alliance Coordinator’s Post

A Proposal for Continued Funding
Keynote Introduction and Overview by the RDAA Chair

The Effectiveness of the Rotherham Dementia Action Alliance

The work of the Rotherham Dementia Action Alliance (RDAA) has already proven that it is possible to achieve wider local social benefits beyond those of the development and implementation of the individual organisational Action Plans it helps establish, develop and monitor. The RDAA has enabled organisations from within and, more crucially outside traditional health and social care planning to help deliver specific community building projects as well as general awareness.

Some practical results so far include the free local Legal and Financial Services Guide and free local What’s on Where Guide for older people. By engaging local private businesses other areas of signposting and advisory initiatives will also develop over time. RDAA is a neutral platform which helps consolidate and cascade information between as many organizations and agencies as possible.

RDAA involvement helps Members become aware of and then flag up the need for early diagnosis and intervention. So effectively private organisations, and other Member organisations, become involved in improving the health and well-being of the community in a very practical way - helping secure the positive outcome of early intervention and crisis prevention in a highly cost effective manner.

The same applies to explaining how RDAA Members can signpost people on to appropriate social support such as their GPs and the Alzheimer’s Society. For example the Memory Cafes have grown partially as the result of integrating a wider group of organisations than public health and social care structures into their awareness and support networks. This is part of local de-stigmatisation in action.

There are also substantial local campaigns evolving in specialist areas; For example establishing Dinnington High School, Rotherham, as a flagship for the roll out of the dementia friendly communities’ agenda in schools. That has had a tremendous impact amongst pupils, staff and clearly benefits local families who are affected or think they may be affected by dementia. That campaign also involves all the private, public and third sectors in one form or another.

There is a clear local cascade effect evident in Rotherham. That is derived from the leadership, motivation and organisation provided by the volunteers in the RDAA Steering Group (and its sub-groups) working in conjunction with the paid Co-ordinator. This means that the RDAA is confident that it can continue to deliver great results at nil or much reduced cost to the public purse.

The RDAA is a significant structural part of not only the dementia friendly communities’ agenda but also of cost effective local community building. Given the focus of the personalisation agenda for Health and Social Care on peer support, integration of all local sectors and value for money it would seem logical to ensure that the good work which has been begun is supported sufficiently to ensure it continues to deepen and broaden.

In Short the work of the RDAA to date could not have been achieved without a paid Co-ordinator. This is further explored in this report.

David Coldrick – Chair RDAA. November 2015
What are Dementia Action Alliances?

Dementia Action Alliances are a national initiative and operate throughout the country. The Action Alliances were created in line with the World Health Organisation's (WHO) directive that the way forward to help people with dementia live well, out of the health care system for as long as possible, was to create dementia societies.

They are social movements with a simple aim – to change society's attitudes towards dementia and cascade knowledge, support and guidance to enable companies, organisations, faith groups, schools, colleges and community groups become dementia friendly.

Dementia Action Alliances and The Dementia Friends initiatives are supported and regulated by the Alzheimer's Society (Annex 1).

Rotherham Dementia Action Alliance

*Rotherham Demetria Action Alliance (RDAA) was formed* late 2013 and was the officially launched in May 2014; a Chair (David Coldrick – Managing Director Home Instead Rotherham) and Vice Chair (Liz Hopkinson - Rotherham & Doncaster Service Manager - Alzheimer's Society) were elected.

During the period up to launch (November 2013 and Feb 2015) the Chair and Vice Chair created local 'sub-groups' and made other links to key organisations within the private, statutory and third sectors. The list of Member organisations has been has broadened since the appointment of Kathryn Rawlings as RDAA Co-Ordinator in early 2015.

Organisations and companies sign up to become members of the RDAA and gain knowledge, via the Coordinator, on how to become Dementia Friendly, creating meaningful action plans that will help people with dementia live well in society. The long term vision within Rotherham is to be recognised as a dementia friendly town. This can only be achieved with high levels of involvement within Rotherham.

The more dementia knowledge within the communities the more we can help to create a community spirit - this is done by cascading dementia awareness. This knowledge gives people a true insight into the world of a person with dementia and help’s to encourage care and tolerance into our communities.

In addition the Alliance looks at dementia friendly physical environments; how a building /area can be designed to help a person with dementia feel more at ease (this work has wider society benefits

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1 WHO [http://apps.who.int/iris/bitstream/10665/75263/1/9789241564458_eng.pdf?ua=1](http://apps.who.int/iris/bitstream/10665/75263/1/9789241564458_eng.pdf?ua=1)
RDAA is a neutral platform which helps consolidate and cascade information between as many organizations and agencies as possible.

In the first 18 months Rotherham Dementia Action Alliance membership totalled 26 organisations including South Yorkshire Fire and Rescue, South Yorkshire Police and the Rotherham, Doncaster and South Humber NHS Foundation Trust...

Once the Dementia Action Alliance Coordinator was in post, from the 23rd February 2015, RDAA membership grew rapidly. There are currently 72 members with up to 121 organisations being worked with to create meaningful action plans.

Summary of work:
- 72 Organisation (or individuals) signed up
- 10 action plans developed or completed
- 23 newly committed organisations
- 16 organisations shown an interest (new) New interest 16
- 121 total Rotherham Dementia Action Alliance new members

There have been 95 additional members since 23rd February 2015.

**Review of Adult Services**

Local Authority Adult Services Directorates, across the country, are reviewing how they deliver services with regard to considering how they can provide a better service with outcomes focusing on personalisation in the ever more difficult fiscal climate of local government funding.

There is an acknowledgment, and research evidences, that when people can are supported within their communities they will stay independent and have increased wellbeing for longer and avoid the decline and dependency that long term residential and traditional outdated day care bring.

Dementia Alliances support this concept and look for ways for people with dementia to be kept safe and remain integrated within their communities for as long as possible by taking a preventative approach and exploring inclusive ways to help people with dementia live well for as long as possible.
**Work generated from Rotherham Demetria Action Alliance**

**Case Study 1**

*RDAA Membership: South Yorkshire Police*

South Yorkshire Police (SYP), in Rotherham, raised the issue that when people with dementia go missing it can be very concerning for offices and very distressing for the person with dementias carers. This opened up discussions and work began to consider how to manage these incidents more affectively.

The *Herbert Protocol* (Annex 2) was created through partnership and co-production working.

The *Herbert Protocol* is a risk management and information gathering tool for use when a person is reported as missing; when someone is reported as missing, it is vital that the police get information as soon as possible. The *Herbert Protocol* tool provides carers and family members with a method to gather relevant information so that it is available to pass to police officers when a person is reported as missing.

Since it was adopted, in Rotherham, the protocol has and is being cascaded as good practice throughout the country - a credit to Rotherham Demetria Action Alliance

*Note: average cost of a missing person is £1325 – £2415: CMPS 2012)*

**Case Study 2**

*RDAA Membership: Solicitors and Financial Advisors*

The need for families to sort their financial arrangements is of high importance. It is a distressing additional issue to contend with and that is not helped due to the variety of information available being vast and varied in quality which can be confusing for families.

At their own cost the *Rotherham Dementia Action Alliance* professional sub group produced a *Financial Guide* (Annex 3) which gives clear guidance on financial advice for families who are affected by dementia. Those involved in the group gained knowledge about dementia to ensure they were equipped to handle and understand the issues that arise when a family is caring for someone with dementia and in the longer term considering the issues surrounding residential /nursing care.

These guides are distributed by many Alliance organisations including *Alzheimer’s Society*, *Age UK*, care providers, General Practitioners (GP’s) and *RDaSH*.

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2 Centre for Missing Person; University of Portsmouth [http://www.port.ac.uk/uopnews/2012/08/06/cost-of-missing-persons-investigation-revealed/]
Case Study 3

**RDAA Membership: South Yorkshire Fire and Rescue**

*South Yorkshire Fire and Rescue* (SYFR) have recognised the potential for the beneficial joint working within the Alliances across South Yorkshire and the inroads into other agencies that this enables- the *Alliance* has a combined membership of 300 including public sector, retail, voluntary sector, private companies and faith communities.

SYFR have provided £149,000.00 funding to *Dementia Action Alliances* in South Yorkshire over 2 years from the *Rescue Safer Communities Reserve for Home Safety Checks*. The *Homes Safety Check* project is important as it allows people with dementia to stay safely in their own homes longer – a person with dementia becomes a far greater risk to themselves and their families’ and neighbours.

*Fire Safety* and *Community Safety* are feature in the establishment of each of the four South Yorkshire areas seeking to become *Dementia Friendly*. Dementia awareness will become embedded in the training programmes of all fire fighters assisting in the recruitment of *Dementia Friends* in each area.

*Note:* The average cost of a house fire in the *Yorkshire & Humber* is £46,000.00\(^3\) whilst an accidental death including a house fire is £1,800,000.00.

Case Study 4

**RDAA Membership: Rotherham NHS Foundation Trust District General Hospital**

*Rotherham Dementia Action Alliance* supports the dementia lead nurse of the *Rotherham NHS Foundation Trust District General Hospital* to consider how to reduce the incidents of people with dementia being admitted to hospital and reduce the time spent in hospital.

With the move to integration and the advent of the *Better Care Fund* health provision has moved from a service of 'cure' to one of 'prevention'. Prevention is key to people living well in society – in their own communities – as they are less likely to have a crisis, which could result in a hospital admission.

The *Rotherham Dementia Action Alliance* believe that the work already undertaken can be built on, through partnership working, to achieve the aims of health and social care statutory organisations.

*Note:* A *Hospital bed costs approximately £250 per day* (NHS England\(^4\) 2014). Research shows that a person with dementia, once admitted, is far more likely to have a longer stay in hospital and is more likely go into full time residential care prematurely on discharge.

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**Case Study 5**

*RDA Membership: Dinnington High School*

Dementia Action Alliances, throughout the country, are working to create a *Dementia Friendly Next Generation*; schools, colleges, youth groups, scouts and guides are signing up as *Dementia Friends*.

Dinnington High School, Rotherham (a coeducational secondary school for pupils aged 11 to 18 years) is a perfect example of how the *Rotherham Dementia Action Alliance* is creating the next generation of *Dementia Friends*. *Dementia Friends* has been built into the Health and Social curriculum and has been well received – the work of the pupils is a credit to the school.

The model used by, *Rotherham Dementia Action Alliance*, to cascade knowledge and interest about dementia to pupils at Dinnington High School is one that the Alliance aims to roll out to schools throughout Rotherham, this is a planned area of work for 2016.

**Case Study 6**

*RDA Membership: Rotherfed and Rotherham Metropolitan Borough Council’s 7 Areas Assemblies*

The *Rotherham Dementia Action Alliance* is working with Rotherfed\(^5\), Area Assemblies and Town Councils to maximise the work of the Alliance within the local communities.

By working in partnership with local communities the Alliance can cascade the concept of *Dementia Friendly Communities* to local business and community groups. By communicating and working with communities the benefits of the Alliances work can be wide reaching.

**Case Study 7**

*RDA Membership Rotherham GP practices*

The *Rotherham Dementia Action Alliance* is working with over 18 General Practice practices in the NHS Rotherham CCG locality; the Alliance cascade dementia knowledge to staff groups and information about local services.

General Practice staff are encouraged to look at their environments to see if practice layout and signage can be improved to become more dementia friendly. This support has been very well received amongst the GP’s themselves and has made an impact on the teams.

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\(^5\) Rotherfed [http://rotherfed.org.uk/](http://rotherfed.org.uk/)
Additional Information and Benefits:  Dementia Action Alliance Coordinator

Rotherham Dementia Action Alliance have been successful in becoming a finalist in the Voluntary Action Rotherham Community Awards for 2015 helping to mark a very successful year since the coordinators post has been in place.

In addition to signing up new members Rotherham Dementia Action Alliance delivers Dementia Awareness and Dementia Friends sessions across the borough – the post has generated over 750 Dementia Friends for Rotherham.

The Dementia Action Alliance Coordinator post is a proven successful way of cascading service information about social outlets, educational tools and resources and information GP’s and Dementia Action Alliance members.

The Dementia Action Alliance Coordinator cascades good practice in care home and amongst care providers. The Alliance is currently working with Rotherham Metropolitan Borough Council and interested residential homes and care providers to form a group to promote good practice and generate interest in new initiatives.

Evidence of need:  Dementia Action Alliance Coordinator

It is estimated that there are 815,000 people living with dementia in the UK (Alzheimer’s Society\(^6\) 2014).

In the Rotherham Metropolitan Borough Council geographical area 3165\(^7\) people are currently predicted to be living with dementia and this is set to rise to 5115 by 2030\(^6\). Those with a ’Dementia Diagnosis’ currently registered with a General Practice (GP) in the NHS Rotherham Clinical Commissioning Group (03L) geographical area total 2165 (HSIC\(^8\) January 2015)

Alzheimer’s Society is a well-established local provider in the Rotherham Metropolitan Borough Council and NHS Rotherham Clinical Commissioning Group’s geographical area. The Society provides a number of services which are person centred and are based on the needs of people with dementia and of the local community.

\(^7\) Projecting Older People Population Information (www.poppi.org.uk).
Conclusion

The Alzheimer’s Society are currently looking to our partners in Health, Social Care, Voluntary and local Business sectors to secure funding for the Rotherham Dementia Action Alliance Coordinators post for a further 12 or 24 months.

The Alzheimer’s Society is requesting the Rotherham Health and Wellbeing Board to contribute to funding the Rotherham Dementia Action Alliance Coordinator post; costings are attached in Annex 4.

South Yorkshire Fire and Rescue have provided an annual contribution of:

- 1st February 2016 – 31st January 2017 £9,600.00
- 1st February 2017 – 31st January 2018 £9,600.00

Alzheimer’s Society is committed to contribute an annual contribution to host the post of Rotherham Dementia Action Alliance Coordinator

Alzheimer’s Society will make a contribution towards costs of:

- 1st February 2016 – 31st January 2017 £1,586.00
- 1st February 2017 – 31st January 2018 £1,598.00

NHS Rotherham Clinic Commissioning Group has committed to contribute:

- 1st February 2016 – 31st January 2017 £5,000.00

Alzheimer’s Society is therefore requesting that the Rotherham Health and Wellbeing Board, and its constituent partner organisations, consider the Society’s request to allow for the current work streams to continue. The Society is seeking the following for each 12 month period:

- 1st February 2016 – 31st January 2017 £20,873.00
- 1st February 2017 – 31st January 2018 £26,239.00
Alzheimer’s Society

Alzheimer’s Society is the UK’s leading support and research charity for people with dementia, their families and carers. Dementia currently affects over 800,000 people in the UK.

The Society provides information and support to people with any form of dementia and their carers through publications, a ‘National Dementia Helpline’, our website and more than 2,900 local services throughout England, Wales and Northern Ireland.

The Society supports health and social care professionals by delivering high quality education, resources and training. Our work also includes the influencing of politicians (local and national) and policy-makers and we campaign for a better quality of life for people living with dementia and their carers and for greater understanding of dementia in the wider society.

We also fund innovative research in the areas of cause, cure, care and prevention. The Society works with scientists and people affected by dementia to ensure that the medical and social research programmes that we fund have a positive impact on people’s lives. We were a founder member of the ‘National Dementia Action Alliance’ which launched the national ‘Dementia Declaration for England’. The Society also launched the high profile ‘Dementia Friends’ campaign which aims to recruit ‘Dementia Friends’ who will commit to take action to improve the life for people with dementia.

Alzheimer’s Society believes people with dementia are experts on living with dementia and we work with those who use the Society’s service in recruitment, training, service development, quality assurance and evaluation.

As detailed within the Alzheimer’s Society’s 2013 Report ‘Dementia: The Hidden Voice of Loneliness’, the Society worked with partner organisations to launch a National Dementia Declaration for England. In this declaration people with dementia and carers described the seven outcomes that were most important to their quality of life:

• I have personal choice and control or influence over decisions about me.
• I know that services are designed around me and my needs.
• I have support that helps me live my life.
• I have the knowledge and know-how to get what I need.
• I live in an enabling and supportive environment where I feel valued and understood.
• I have a sense of belonging and of being a valued part of family, community and civic life.
• I know there is research going on which delivers a better life for now and hope for the future.

These seven core principles underpin the Society’s work and are central to the Rotherham Dementia Action Alliance service.

Herbert Protocol (text)

An initiative supported by Alzheimer’s Society
T: 0845 3000336 (Mon-Fri 0830 – 1830) Web: www.alzheimers.org.uk

The Herbert Protocol - A risk reduction tool for people and families living with dementia (Version for a person living at home)

What is this for?
These forms are designed to make sure that, if someone goes missing, the police can get access to important information about that person as soon as possible.

If a relative cannot be found, then this is a deeply distressing and upsetting time for their family and friends. Being asked by a police officer to remember all sort of different information can add to this stress, and these forms are designed to remove some of that worry.

When should I complete them?
As soon as possible! These forms can be completed at your leisure, with no time pressure or urgency. That said, the sooner they are ready, the quicker they can be used if they are needed.

When you have completed the form, keep it safe – make copies and keep them in a handy place, such as next to your phone, in a handbag or day bag. Consider giving them to family & neighbours.

Consider whether it would be a good idea to take a photograph of the form to store it on your mobile phone or email it to yourself and save email with the attached document on your mobile phone. Both these options give you easy access to the information.

How much detail is needed?
Whilst sometimes more information is better, police officers want an overview rather than in depth detail. So while we need to know, we don’t need to know everything! If you are writing the information by hand, please try to make sure that it is easily readable for someone perhaps not used to your handwriting.

What will happen to this information when I have completed the form?
There is no need for the police or anyone else to have access to this information unless the person to whom it refers goes missing. You keep the information and hand it over when the police need it – it will be used to help the police to find your loved one as soon as possible, and nothing more!

With your permission, we will create what is called a ‘location tag’ on your home address. This is just a note on the police systems, which lets us know that you have this information sheet available. We may also ask some of our community officers to come and pay you a visit, to make sure you are ok, to offer some crime prevention advice and just to make contact with you and your family. The Alzheimer’s Society will also ask to speak with you and yours.

*We will never share your information with anyone else, unless as a part of a live investigation where there is sufficient justification in the interests of a person’s safety.*

**What should I do when I find out that my relative / friend is missing?**

This is vital – if you can't find a person after a couple of minutes looking, then you **MUST call the police on 999.**

It is quite normal to worry about calling 999. Some people are worried that they will be criticised for calling the police – if you are worried about a person's safety, then this will not happen!

**Minutes saved can mean lives saved!** The sooner the police know that someone is missing, then the sooner officers can start looking for them.

**What will the police need to know?**

When you ring 999, the operator will ask you which service you want – tell them ‘POLICE’

The police operator will then answer the call. When the police operator speaks to you, it is important that you tell them exactly what the concern is, for example, "I cannot find my husband / wife. They may have gone missing and they have dementia"

**Tell the police operator that you have the Herbert Protocol document for officers**

The operator will then ask you several questions. One of the first questions will be about your address, or where you are calling from.

**Do not worry that talking to the operator will slow down the police response!**

**The systems are in place to allow them to talk to you at the same time as officers are being sent to find your loved one.**

They will ask:

- When was the person last seen? How long ago, and where – be as specific as you can.
- What were they wearing? They will ask for a description of the clothes the person was last seen wearing, and anything they might be carrying, such as a bag or walking stick etc.

If you are away from home, and don’t have the information sheet with you – don’t worry!

The information contained will be of great use for being able to coordinate the search for your loved one. You will be feeling upset and worried for their safety. This is completely natural, and the police officers will make sure that you are supported throughout the process.

**PLEASE REMEMBER**— this form, and the information it contains should be regarded as an additional measure to help ensure a person’s safety. It should NOT be the only approach taken. Looking after someone with degenerative conditions is one of the most difficult and upsetting things anyone has to deal with – support is available through the NHS, various charities and other groups local to you. They can officer advice, support and guidance.
Vulnerable Person Profile

Fill in these sections and keep it in a safe place, where it can easily be located if the person it refers to goes missing. You may want to make several copies, which can be kept safe by neighbours or relatives.

The checklists below are indicative – do not worry if you do not have or cannot get all of the information it asks for - some of it will not apply to everyone.

<table>
<thead>
<tr>
<th>Name of Vulnerable person:</th>
<th>Date of Birth</th>
</tr>
</thead>
</table>

### Medical Information
- Current Diagnosis?
- Medical Conditions?
- Any particular fears or phobias (such as fear of water / heights etc.)?
- How easily can the person walk? How far could they get before becoming tired? Do they need a stick or other aid? Can they move between furniture without help?
- How may they react to being upset or scared?
- If they don’t have their medicine – are there any short term risks?

### Places or addresses of note
- Previous home address?
- Childhood address?
- Family addresses?
- Places of interest or significance – could be old school, a favourite walk or place to visit, a cemetery, former place of work or a childhood home

### Jobs, Interests and Hobbies
- Where did / do they work? Most recent AND historic
- Favourite pub / club / sports ground / allotment etc
- Favourite outdoor activities? Bowling? Cricket? Fishing?
- Library? Cinema?
- Regular holiday destinations
<table>
<thead>
<tr>
<th>- Any particular or special interests?</th>
</tr>
</thead>
</table>

### Weekly habits

<table>
<thead>
<tr>
<th>- Which shops are used?</th>
</tr>
</thead>
<tbody>
<tr>
<td>- Favourite cafe?</td>
</tr>
<tr>
<td>- GP / Nurse / Clinic / Group</td>
</tr>
<tr>
<td>- Church/ Mosque / Synagogue / Temple?</td>
</tr>
<tr>
<td>- Houses / friends to visit (now and historic)</td>
</tr>
<tr>
<td>- Chemists?</td>
</tr>
<tr>
<td>- Hospital?</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>- Bus Pass?</th>
</tr>
</thead>
<tbody>
<tr>
<td>- Access to money – cash card, cheque book, cash usually carried</td>
</tr>
<tr>
<td>- Mobile phone? Number?</td>
</tr>
<tr>
<td>- Local transport – nearest bus stop: to where?</td>
</tr>
<tr>
<td>- Nearest train station?</td>
</tr>
<tr>
<td>- Car? Able to drive? Previously driven?</td>
</tr>
</tbody>
</table>

### Anything else?

### Do you have a recent photograph? Is it readily available, and a good likeness?

*Photo*
Annex 3

Financial guide (attached PDF)
THE LEGAL SIDE OF DEMENTIA

WHAT KEY THINGS DO YOU NEED TO CONSIDER?

When someone you care about is increasingly unable to make decisions about their finances or health you may need to consider a Lasting Power of Attorney (LPA). An LPA is a way of nominating a trusted friend or relative to look after their affairs.

MAKE LASTING POWERS OF ATTORNEY

There are two types of Lasting Powers of Attorney (LPA) that you can apply for:

PROPERTY AND FINANCIAL AFFAIRS LPA

This allows for the appointment of someone (an Attorney) to deal with financial affairs including paying bills and applying for benefits on behalf of the person (the Donor) who is having difficulty managing those financial affairs for themselves. This can be used as soon as it’s registered.

HEALTH AND WELFARE LPA

This allows for the appointment of someone (an Attorney) to deal with decisions about health and welfare. It can include decisions about medication and treatment, where they will live and who will visit them.

An attorney can only use this LPA when the Donor has lost the capacity to make these decisions for themselves.

WHAT TO DO NEXT – CAPACITY & CERTIFICATE PROVIDER

An LPA can only be made when the Donor has the mental capacity to understand the document, the powers they are giving to the Attorneys and the implications.

In order to put an LPA in place, someone known as a Certificate Provider must confirm that the Donor has the necessary capacity to make an LPA. The Certificate Provider is often quite the treating consultant at the Memory Clinic.

It is often the case that the Memory Clinic will suggest an LPA be put in place once a diagnosis has been given.

WHY REGISTER THE LASTING POWER OF ATTORNEY?

Please bear in mind that an LPA must be registered with the Court before it can be used by the Attorney. This means you’ll need to factor in the time it takes to deal with registration, which is typically 10 – 12 weeks. However, the timescale will vary depending upon each Court’s workload.

APPLYING TO THE COURT OF PROTECTION

If the Certificate Provider is unable to confirm that the Donor has the necessary capacity to put in place an LPA then steps needs to be taken in order to appoint a Deputy.

An application will need to be made to the Court of Protection before any financial decisions can be taken. The Court of Protection is the Court that has the power to make decisions relating to people who have lost their mental capacity.

If a person lacks capacity to make an LPA, family members or friends can apply to be appointed as a Deputy on their behalf. Once appointed, the Deputy will be able to make financial decisions on behalf of the person who lacks capacity, subject to the overall control of the Court. For example, the Deputy would have the legal authority to sign papers relating to the sale of the property and to look after the proceeds of sale.

If something needs to be completed quickly such as helping the house special directions might be needed from the Court.

As with registering for an LPA, it takes time to appoint a Deputy. This is typically 4 – 6 months, although it can take longer.

MAKING A WILL

WHY IT’S IMPORTANT TO MAKE A WILL

The next thing to consider is to ensure a Will is in place. A Will ensures that when you die, your money and possessions go to the people you choose. If you do not have a Will, the law will dictate who will benefit from your estate.

This means it is important to make a Will whilst you still have testamentary capacity. If you have dementia, you may still have testamentary capacity to make or change a Will.

WHAT IF YOU DON’T HAVE TESTAMENTARY CAPACITY?

In this situation, only the Court of Protection can make a Statutory Will on your behalf.

Partnerships of the person with dementia may also wish to consider making or changing a Will. If you wish to leave your estate to the person with dementia, you should consider setting up a Trust to ensure their income is protected.

This will also help to prevent their children from taking their inheritance they are due to receive.

WHAT ABOUT YOUR FAMILY HOME?

You can make provision for your property in your Will to your children for example, to ensure that they inherit what you have worked hard for.

As you get older you may require advice on a number of property transactions in addition to the above. You may also need to consider moving home to find accommodation that’s more suitable for you.

WHAT IF YOU ARE ELDERLY?

This can range from planning a monthly budget, to understanding how to fund care fees, applying for state benefits and ensuring that assets are properly managed and protected. With the right support and advice this can all be taken care of.

PUTTING A FINANCIAL PLAN TOGETHER

The financial consequences of dementia may begin to be felt well before you need to consider funding the cost of care. If your parent or loved one has always managed their own finances (or that of the family) they will probably need help very quickly.

By seeking advice at an early stage, families can create a plan to make sure that things continue as normal during what may be a difficult time. A professional adviser will help you to work with the person affected by dementia, starting from the immediate need to manage their income through to the potential need for care or assistance. They will guide you through the options and remove many of the uncertainties and concerns about the future.

THE FINANCIAL SIDE OF DEMENTIA

Following a diagnosis of dementia one of the most daunting things to consider can be ensuring that the financial side of things is taken care of.

This can range from planning a monthly budget, to understanding how to fund care fees, applying for state benefits and ensuring that assets are properly managed and protected. With the right support and advice this can all be taken care of.

Putting a Financial Plan Together

The financial consequences of dementia may begin to be felt well before you need to consider funding the cost of care. If your parent or loved one has always managed their own finances (or that of the family) they will probably need help very quickly.

By seeking advice about financial support, you can create a plan to make sure that things continue as normal during what may be a difficult time. A professional adviser will help you to work with the person affected by dementia, starting from the immediate need to manage their income through to the potential need for care or assistance. They will guide you through the options and remove many of the uncertainties and concerns about the future.
FUNDING THE COST OF LONG TERM CARE

One of the biggest concerns for those with dementia, and their families, is how to fund the cost of both immediate and longer-term care. Although state benefits such as Attendance Allowance are available, it can be difficult to find out about the wider range of support that local authorities and the NHS can offer. This is especially true when trying to understand the impact of means testing and the likely implications of self-funding.

The average cost of residential care in the UK is currently estimated at £550 per week. If nursing care is also required, this can rise to £720 per week. The average cost of care in your home is £15 per hour (source: Local Authority Care of Older People, UK market report 2013).

It is therefore not surprising that one in four people who fund their own care ran out of money (source: Partnership 2013), leading to potential compromises regarding their future care. Most commonly, this is because they do not consider all the options or take proper advice.

With financial planning it may be possible to fund care for as long as required, whilst safeguarding as much capital as possible. For this reason, consulting with a specialist financial adviser is essential from both a health and financial perspective.

PAYING FOR CARE - OPTIONS

For those required to pay for their own care, there are a number of different ways this may be done depending upon your circumstances:

1. Own income
2. Family contributions
3. Savings accounts
4. Telecoms
5. Care Fees Plan

1. Own income
   - You may receive sufficient income to pay for care in full, or as a “top-up”. This income could be from a number of possible sources:
     - Pensions
     - Investment income
     - Rentable property
     - Attendance Allowance
     - Nursing Care contribution (if applicable)
     - Funding from other family members

Details of state benefits can be found at www.gov.uk/browse/benefits

Even if your income appears to be enough to cover the cost of care in full, take advice. It is likely that improvements can be made.

2. Family contribution
   - Your family may be able to cover some or all of the cost, or difference in cost, as a “top-up”.
   - If neither of these are an option, you will need to raise money either by accessing savings or investments, reliving money from your home via an equity release plan, or selling the home.

3. Savings accounts
   - This includes money held in independent annuities, Cash, Individual Savings Accounts (ISAs), and National Savings. Very little risk, but with current rates of interest being so low you will need to ensure your capital is not eroded too quickly.

4. Investments
   - There are many possibilities here from investment bonds and unit trusts to shares. However, the most profitable are usually the highest risk. Therefore a balance may need to be struck.
   - There is no guarantee that values will not fall and put your capital at risk.

Again, this is where advice from a professional can be invaluable by helping to ensure your savings and investments provide you with a predictable and consistent income for funding care costs.

3. Care Fees Plans (also known as Immediate Needs Annuities). These are specialist insurance plans designed to convert capital into income to help meet care fees. In return for a one-off lump sum you receive a guaranteed tax-free income for life.

YOUR PROPERTY

The proceeds of a house sale can be used to support any of these options if other assets on their own are insufficient.

MANAGING SPENDING

SUPPORT AND MONITORING

It’s also a good idea for partners or family members to meet regularly with a Financial Adviser to monitor and understand any changes in circumstances as they develop and to adapt their financial arrangements to take account of them. This can provide genuine peace of mind for everyone when it really matters.

Looking after your finances can have a dramatic effect on your ability to pay for the type of care or care home that you require. Seeking professional advice from a regulated financial adviser will help you achieve this.

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### Annex 4

<table>
<thead>
<tr>
<th>Services Provided</th>
<th>Year 1 01/02/2016 to 31/01/2017</th>
<th>Year 2 01/02/2017 to 31/01/2018</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Rotherham Dementia Action Alliance Coordinator</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Salaries plus on costs</td>
<td>£26,337.00</td>
<td>£26,612.00</td>
</tr>
<tr>
<td>Dementia Action Alliance Coordinator 35 hrs. pw</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Services Manager 1.75 hrs. pw</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Learning &amp; Development</td>
<td>£423.00</td>
<td>£428.00</td>
</tr>
<tr>
<td>Volunteer costs</td>
<td>£822.00</td>
<td>£831.00</td>
</tr>
<tr>
<td>Mileage</td>
<td>£1,210.00</td>
<td>£1,222.00</td>
</tr>
<tr>
<td>Office costs e.g. rent printing, stationery, postage etc.</td>
<td>£1,586.00</td>
<td>£1,598.00</td>
</tr>
<tr>
<td>IT costs</td>
<td>£1,195.00</td>
<td>£1,205.00</td>
</tr>
<tr>
<td>Other essential &amp; local support costs including Finance, HR, Health &amp; Safety, Safeguarding &amp; risk, evaluation and support from the Regional Dementia Action Alliance</td>
<td>£5,486.00</td>
<td>£5,540.00</td>
</tr>
<tr>
<td><strong>Sub-total</strong></td>
<td><strong>£37,059.00</strong></td>
<td><strong>£37,437.00</strong></td>
</tr>
<tr>
<td>NHS Rotherham Clinical Commissioning Group</td>
<td>£5,000.00</td>
<td>n/a</td>
</tr>
<tr>
<td>South Yorkshire Fire &amp; Rescue contribution to total cost</td>
<td>£9,600.00</td>
<td>£9,600.00</td>
</tr>
<tr>
<td>Alzheimer’s Society contribution</td>
<td>£1,586.00</td>
<td>£1,598.00</td>
</tr>
<tr>
<td>Balance: Rotherham Health and Wellbeing Board and constituent partners</td>
<td>£20,873.00</td>
<td>£26,239.00</td>
</tr>
</tbody>
</table>