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Acknowledgements

The RCSLT and the Project Team would like to thank all those who assisted in drafting this guidance. We have received valuable advice from many reviewers from within the speech and language therapy profession who have given up their time generously. Experts on particular topic areas from related professions have also been consulted and assisted with detail. Service Commissioners and senior managers have commented on drafts showing patience and fortitude!

We would particularly like to thank the many who contributed to the focus groups which helped to shape this document.
CONTEXT

The aim of this section is to set out the context for this resource. This work forms part of a range of tools which can support leaders with service planning and delivery, in line with both government and local priorities.

It is essential for service providers to demonstrate quality and productivity and to:

- show value for money
- be able to provide a strong financial argument for the need to invest in services for people with speech, language, communication and swallowing needs
- demonstrate improvements in outcomes for individuals, families and society

Value for money is not about being the cheapest option but about delivering the most return (impact, best outcomes) for a given investment over time.

The key drivers for change to services include:

1. The broad context, which can be divided according to the following factors:
   - Political and Legislative factors
   - Economic factors
   - Social factors
   - Technological factors

2. The near or local context, including:
   - Localised policies
   - Addressing local needs
   - Service provision
   - Workforce
   - The evidence base

THE BROAD CONTEXT (MACRO-ENVIRONMENTAL ANALYSIS): FACTORS FROM THE WIDER WORLD

The Macro-environmental analysis commonly takes the form of a PEST analysis:

Political and legislative factors
Economic factors
Social factors
Technological factors

**Political and legislative drivers**

Devolution has resulted in changes to the powers of the different institutions across the UK.

The government in power at Westminster maintains responsibility for policy and legislation in relation to key areas including: tax, benefits, foreign affairs, international development,
trade and defence for the four countries of the UK. Government in Westminster is also responsible for health, social care and education in England, but these areas are devolved for Northern Ireland, Scotland and Wales.

As a result of devolution, each country of the UK may have different parties in power, with the possibility of increasing powers in the future. The impact of this is the diversification of policy and direction of travel.

**Legislative drivers**

The main areas of UK-wide legislation that are relevant include the following themes:
- Human Rights
- Disability Discrimination
- Equality

Though there is different local interpretation, these far-reaching legal instruments define the rights and responsibilities of people and those commissioning and providing services for them.

Public protection has also been strengthened through the introduction of registration of professionals, for example, through the Health Professions Council.

There is separate legislation relating to health, education and social services in each of the devolved administrations in England, Northern Ireland, Scotland and Wales.

**Economic**

The current challenging economic backdrop will have a significant impact on the financing of public services, with local planners and commissioners prioritising services which are value for money, evidence based and releasing cash through innovation.

**Social**

In order to plan and deliver services, it is essential to identify the demographic factors relevant to speech and language therapy (SLT) and the challenges that these bring.

- The population is aging: people are living longer.
- The birth rate is falling: most families are having fewer children
- The infant mortality rate is also falling, with more children surviving premature birth or health problems or injury in infancy.
- The urban population is growing.
- The proportion of the population in employment is falling.
- The proportion of the population with English as an additional language is increasing, particularly in urban areas.
THE NEAR OR LOCAL CONTEXT

Localised policies

Central to the new reforms is the emphasis on local decision-making within a national framework. Across the four countries of the UK there are requirements to provide services to accord with local need and influence. In England there is a particular focus on increasing the range of potential providers (plurality of provision) with commissioners having a role to stimulate the market.

For each country, arrangements have been established to assess whether commissioners are achieving better health outcomes for the local population. Part of this process will be an assessment of how well commissioners are performing against specified competencies/indicators/targets. For example, in Northern Ireland these targets are based upon high-level outcomes linked to local strategies.

With the devolution of power to local levels, there is a focus on developing more robust accountability. There is an emphasis on joint working to support integrated commissioning, service planning and provision across health, social care and education.

There are different approaches to this development with different structures and commissioning and performance management arrangements being established across the UK. The dominant theme in strengthening accountability is “putting service users at the centre” with respect to:
- Access and self-referral
- User voice at strategic to operational to individual case management
- Population/local engagement
- Information and advice for users, parents/carers
- Patient Rights
- Self management of conditions

Some localities will be commissioning or planning speech and language therapy services as a single service whilst others will be commissioning integrated services, cutting across traditional boundaries, with health services integrated with education or social services. In many areas, this has already happened for children’s services.

It is recognised that, often, no single agency can deliver best outcomes for their service users by working in isolation. Joint commissioning is advocated wherever the meeting the needs of individuals requires contributions from a number of agencies.

Similarly, some service planners or commissioners will be organising services around disease groups, such as services for persons who have survived a stroke. In either case, it will be important for speech and language therapy managers to liaise with other services to ensure that SLT provision is incorporated in their service plans.

Special arrangements are in place for commissioning services for unusual, low incidence or costly interventions. Speech and language therapy managers should identify the specialist commissioning procedures that may be required for individuals requiring
particular interventions such as costly augmentative communication aids, protracted or intensive interventions.

Addressing local needs

In general terms, the UK is experiencing a number of long-term demographic changes (some of which are identified above).

There is significant local variation within these general trends. It is important to understand what these changes and variations imply in relation to the provision of local SLT services. Other local factors to be taken into consideration include: employment, cost of living, housing, transport and, particularly, levels of deprivation.

There are information resources available online from which planners, commissioners and providers can find out more about local and regional demographic factors. Some of these can be found signposted on the RCSLT website www.rcslt.org.

Local public health teams will also be able to sign-post local services to relevant data and information for their area.

There will also be learning from data collected by services. The RCSLT has developed an online tool called Q-SET, the Quality Self- Evaluation Tool to help you collate local SLT service derived information http://www.rcslt.org/resources/qset. Q-SET should be used alongside national and local data to support service planning and evaluation of service delivery.

Through completing Q-SET, provider services can:

- use the resource every 9-12 months to review progress in meeting action plans and to demonstrate service enhancement
- compare their service with other similar service types e.g. urban, rural, acute, community, adult, paediatric, education, 3rd sector
- demonstrate that their service meets the needs of the service users
- identify areas of strength and generate action plans relating to areas of development.
- submit the results as part of the evidence for a clinical audit
- retain ownership of the monitoring and development of services ensuring that strong professional standards are maintained in the context of multi-agency teams

Service providers completing Q-SET will support commissioners to:

- reduce the ‘postcode lottery’ of service availability and quality
- have high quality information that is relevant and accessible
- have an overview of developments, trends and initiatives within the service
- have accurate and timely statistics to support performance management and monitoring
- collect data to contribute to the debates on benchmarking. Where benchmarks do not yet exist Q-SET will enable Commissioners to contribute to this in the future
- collect examples of good practice to inform other pieces of work and the development of services as a whole.
Locally derived information will help SLT services to illustrate:
- the numbers of patients/clients seen
- sources of referral
- amount of resource used in providing a service to the client e.g. number of sessions and skill mix
- nature and severity of the disorder, disability, psychosocial impact at the onset of intervention
- nature and severity of the disorder, disability, psychosocial impact at the completion of intervention.
- level of satisfaction with the service.

Service provision

Speech and language therapists have a role in delivering specialist and targeted support to clients, carers and their families. Speech and language therapists can also reduce long-term demands on services by addressing immediate needs that arise from circumstance rather than underlying impairment. Providing training for the wider workforce is integral to the speech and language therapists core role, as outcomes for people with speech, language and communication needs SLCN are improved when the whole workforce is able to contribute appropriately to care pathways.

SLTs also work with the wider workforce contributing to the public health agenda, promoting health and well-being in respect of communication and swallowing. There is little awareness outside the profession of the role of speech and language therapists in preventing the development of speech and language impairments and the further impact and consequences of different speech, language and communication disorders upon health, education, social integration and employment.

The challenges of meeting the speech, language and communication needs (SLCN) of a given population are best understood through a social (participative) model. Key elements of a total service specification will start with:
- identifying the needs of the service user, parent or carer for support and information
- identifying/assessing and diagnosing specific SLCN and providing appropriate intervention.
- considering needs of service users within the environments they encounter
- training the wider workforce that interfaces with them to maximise opportunities for positive outcomes.

The balanced system (diagram 1) below illustrates the wider context for how SLTs contribute to this range of activities. The needs of service users should be considered in service specifications. The role of SLTs in supporting the active participation of service users in service planning, adapting the environment and enskilling the workforce is as relevant as the SLT role in identification and intervention.
Workforce

Careful planning of services, including joint commissioning, will help to shape the workforce and inform the skill mix required to deliver high quality services, improve outcomes and support value for money. Because the commissioning and planning of services relies on the evidence base for a given type of SLCN or model of practice, it is essential that clinical and managerial expertise from speech and language therapists is available to support innovation and quality of service design.

Speech and Language Therapists, as part of the wider workforce, may be employed by a range of organisations, including the third sector, social care and education or be working as private practitioners.

Equal Access to services is of importance to local decision makers. Local demographic profiling will inform workforce requirements. For example, bilingual staff and support workers are required in most areas to meet the needs of diverse communities. The appropriate skill mix should enable services to be family-centred and be culturally and linguistically appropriate and responsive. It may be necessary to consider increasing home delivered services or providing services in unusual locations.

The RCSLT also acknowledges the important role that Assistants and Support Workers have in the delivery of effective speech and language therapy services. Assistants and Support Workers are integral members of both speech and language therapy and multi-disciplinary teams, engaged in a wide range of clinical settings with diverse client groups, duties and responsibilities. [http://www.rcslt.org/aboutslts/rcslt_statement_v3.pdf](http://www.rcslt.org/aboutslts/rcslt_statement_v3.pdf)
In order to support more effective use of skill mix, SLT services also need to provide education and training of the wider workforce and not be focussed solely on direct patient/client care. For all services, this is critical to secure the appropriate balance of cost-effective universal, targeted and specialist services.

**PRACTICAL CONSIDERATIONS**

Many people involved in strategic planning, commissioning or reviewing services will not be familiar with speech and language therapy, its objectives, the needs of clients requiring speech and language therapy, the principles driving the profession, or the evidence base and the following points may support people.

- Where possible, draw on the evidence base.
- Communicate clearly and succinctly.
- Avoid using acronyms and provide a glossary of terms.
- Do not assume knowledge of local arrangements or the requirement to interface with other agencies.
- Set your service in the context of local priorities.

The RCSLT’s Communicating Quality 3 (CQ3) provides clear guidance on care pathways, clinical standards and issues related to quality assurance. This information should be used in submissions to support commissioning quality services.

The following guiding principles have been adopted and apply to all client groups. Services are to:
- be family centred and culturally and linguistically appropriate and responsive
- be comprehensive, coordinated and team based
- work with and communicate effectively with other services meeting the needs of the client
- be evidence based
- ensure equal access
- involve the family and carers
- include training and education of co-workers
- ensure practitioners continuing professional development and appropriate support.

Evidence of the impact of the service will be important to commissioners and providers. Providers will need to demonstrate the impact of their service, particularly when services are being reviewed. Determining the objectives of the service will support the process of outcome measurement. SLT services will need to provide information on outcomes achieved and levels of client satisfaction. Some of this information can be gathered through use of the RCSLT’s Q-SET tool, as detailed above.

Managers of speech and language therapy services will need to equip themselves to engage effectively and positively with those who are commissioning or monitoring services. They will need to:
- identify who is commissioning or responsible for overseeing different services. For example, health commissioners may be working with commissioners for education/head teachers. It is important to identify who is taking the lead for each aspect of the service delivery in the locality.
- establish good working relationships and effective communication with those commissioners and planners for their area of responsibility.
- be aware of local priorities and commissioning plans and strategies.
- have a good understanding of the commissioning/planning/monitoring framework for the locality
- be equipped with local data, knowledge and evidence to the tendering process
- be clear of the unique contribution of the service to improving health, employment, education and social outcomes
- be able to clarify and demonstrate local working partnerships and collaborations
- provide data describing the service provided, (numbers and types of patients, numbers of attendances, health and social outcomes etc).

The RCSLT has developed a range of resources to support its members with Continuing Professional Development. CPD is a regulatory requirement for all SLTs and this requires all HPC Registrants to demonstrate how the CPD they have undertaken has sought to enhance service delivery and to be of benefit to service users. The RCSLT has endorsed this requirement through its own CPD standards. [http://www.rcslt.org/cpd/resources](http://www.rcslt.org/cpd/resources)
THE EVIDENCE BASE

The commissioning and planning of services must be informed by the evidence base of effective practices.

This Resource Manual SLCN is based on a synthesis of existing published research. The threshold for inclusion in the syntheses has favoured the most scientifically robust research methodologies which have often reflected medical (impairment) rather than social (participative) models of care.

In the section summaries, emerging practices that have not been included in the evidence synthesis, are referred to and should be considered alongside the syntheses. This tension between empirical evidence resulting from robust research, which by definition is retrospective, and the needs to encourage innovation and service re-design to support improvements in outcomes for people with speech, language, communication and swallowing difficulties is natural and unavoidable. Emerging practice will not have the same evidence base and therefore less empirically stringent measures of evidence need to be taken into account for these areas including professional consensus and measures of service user, parent or carer experience. However, because of the value of some emerging innovative practice, they have been included in this resource.

An overview of the methodologies employed in identifying practices that are included in this resource accompanies this document.

*Using these resources*

Speech and language therapy managers can assist commissioners by understanding their agenda and the objectives that they are to be assessed on.

The Royal College of Speech and Language Therapists is providing these resources to assist speech and language therapists in gathering the core data required to support service tendering agreements, service planning, monitoring arrangements and/or where services require specification.

Each part of these resources is focused on a specific area.

The resources provide:

- *The Contextual Synthesis.* This includes definitions, information on the incidence and prevalence of the disorder, key contribution of speech and language therapists, consideration of the implications and broader consequences of the disorder.
- *The Synthesis of Key Literature.* This summarises the evidence of the impact of speech and language therapy.

Each section within these resources gives succinct information to inform the factual content for any service planning activity. These include:

- Key points
- Topic –What is [the condition]?
- How many people have [the condition]?
What causes [the condition]?
How does this condition affect individuals?
What are the aims/objectives of speech and Language therapy interventions for [this condition]?
What is the management for people with [this condition]?
What is the evidence for Speech and language therapy interventions in [this condition]?
Studies
Assessment methods
Speech and language therapy interventions
Summary
References

This information will need to be put into context, using local information.

Other guidance and resource materials

It is recognised that service managers may wish to amplify or clarify, an aspect of their service by providing reference to other national or local research of relevance.

The RCSLT has a range of resources which can be used to further support and inform the commissioning, planning and provision of services for people with speech, language, communication and swallowing needs. These can be found on the RCSLT website: www.rcslt.org

The RCSLT is grateful to the experts from within the SLT community who contributed to the evidence published in this document.
METHODOLOGY FOR SYNTHESIS OF LITERATURE

Introduction

The focus of the interventional synthesis within these briefings is to provide a synopsis on the effectiveness of speech and language therapy interventions for each specific condition.

The interventional syntheses are produced by reviewers within the Information Resources Section (within the Health Economic and Decision Science Section) at the School of Health and Related Research (ScHARR). Information specialists/reviewers for this bulletin were Diana Papaioannou and Anna Cantrell.

Methodology

The interventional syntheses are not intended to be a full systematic review within each topic area. However, they draw upon systematic review techniques to ensure that the syntheses are developed according to systematic, explicit and transparent methods. The intention of the syntheses is to consolidate twenty articles which represent some of the best research for each topic area.

Literature searching

Systematic literature searches were undertaken to identify a range of evidence for each interventional synthesis. The interventional syntheses do not attempt to consolidate all research within a particular topic area; rather they aim to present a careful selection of the most current research within that field. Therefore, the approach adopted for the literature search aims to be comprehensive reflecting this systematic and explicit approach.

Firstly, search terms were selected within the project team drawing on the expertise of four speech language professionals. This involved listing all possible synonyms describing the condition or population (for e.g. children/infant, stuttering/stammering) and combining those with terms to describe speech and language therapy. Terms were used in both free text and thesaurus searching. The following databases were used:

- ASSIA
- CINAHL
- The Cochrane Library (which includes the Cochrane Database of Systematic Reviews, Cochrane Central Register of Controlled trials, Database of Abstracts of Reviews of Effects, Health Technology Assessment Database and NHS Economic Evaluations Database).
- Linguistics and Language Behaviour Abstracts
- MEDLINE
- PsycInfo

All references retrieved from the literature searches were entered onto a Reference Manager Version 11 database using appropriate keywords.
Selecting and obtaining relevant articles

Articles for inclusion were selected to illustrate the range of good quality evidence within each topic area. An initial screening of articles was undertaken by the Information specialists/reviewers who adopted the following principles:

- Articles must be empirical research evaluating the effectiveness of a particular speech and language therapy intervention
- Only articles published in English language are included.
- In general, only the most current (1998-present) literature is included. However, exceptions were made to this if a particular article was felt to be important to include.
- Where possible higher level evidence was included (systematic reviews, randomised controlled trials). However, this research did not always exist in every topic area.
- Efforts were also made to seek out literature that provided a range of perspectives on interventions for each topic area, i.e. both quantitative and qualitative research.

Following initial screening, the remaining articles were examined by two members of the team; each having considerable speech and language therapy knowledge and experience. Approximately, twenty articles were selected by the two reviewers with disagreements being resolved by a third reviewer.

Assessing the quality of relevant articles

Formal quality assessment of the articles was not undertaken. Instead, quality assessment involved using checklists as a guide to give an indication of the overall quality of studies and highlight the main good and bad aspects of each study. For each interventional synthesis, the included study designs are listed and the problems with each study design noted. General observations on study quality are made and common errors within the studies, where appropriate, are specifically noted. The checklists used are one for quantitative and one for qualitative studies from the Alberta Heritage Foundation for Medical Research.

Additionally, when an identifiable study design was used, the appropriate Critical Appraisal Skills Programme (CASP) checklist was selected.

Syntheses of the twenty articles

Each article was read in turn by one of the Information Specialists/reviewers. The key points were summarised including the objective of the study, the participants’ characteristics, the methodology, the intervention, results and limitations. From this, articles were grouped into themes according to the factor being investigated (for e.g., length of intervention, personnel carrying out intervention, family involvement in treatment, nature of disorder). Results were summarised and drawn together within each particular theme and a summary paragraph provided at the end.

These syntheses first went out for review by selected individuals, identified by the research team, with particular expertise in the delivery or management of services to the

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specific client group. Comments were included in the second draft, which was then dispatched to those selected by the Royal College Speech and Language Therapists who were invited to attend a focus group day. These therapists gave detailed consideration to their specialist area and contributed to the more general discussion of one further area. Issues to be captured in the key points were also identified within the focus groups. These comments contributed to the third draft of the syntheses, which again went out to reviewers. In some cases, further work was required in order to modify the wording and reflect discussion.

### Checklist for service managers involved in commissioning services

Have you presented incidence and prevalence figures and local demographic trends for the conditions in your area?

Have you provided information on local access and use of services in the context of the number expected and highlighted your approaches to inequalities?

Have you consulted systematically with users to inform development of this commissioning proposal?

Does your proposal fit/link with local cross agency priorities?

Have you outlined the range of services provided including training?

Have you made clear how this fits with future planning for your service over the next 3-5 years?

Have you stated the assumptions which underpin your thinking in the plan and for future developments?

Have you offered predictions about the likely impact of investment in the proposal?

Have you made clear where the risks are and what contingency plans you have put in place?

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RCSLT RESOURCE MANUAL FOR COMMISSIONING AND PLANNING SERVICES FOR SPEECH, LANGUAGE AND COMMUNICATION NEEDS

DEMENTIA (UPDATED IN 2013)
1. **Key Points**

1. Speech and language therapists have a unique role in identifying and analysing the specific nature of the speech and language impairment of persons with suspected or actual dementia. They can contribute to differential diagnosis and facilitate the identification of retained abilities and comorbidities (e.g. hearing loss).

2. Speech and language therapists have a unique role in identifying the nature of eating and swallowing problems.

3. Difficulties with social communication is a predominant feature in dementia and can reduce access to recreation, employment, social integration, including forming relationships and expressing personality. It has a major impact upon the quality of life. Speech and language therapists can assist by slowing the decline or reducing the impact of the communication impairment, and by supporting carers.

4. Communication difficulties are associated with increased prevalence of challenging behaviour.

5. Improved communication has an impact on behaviour, social skills, peer relationships and self-confidence.

6. Speech and language therapist should be integral members of services and multiagency teams supporting people with dementia their families and carers.

7. Persons with dementia may present in different ways, and have varying profiles of retained abilities and different needs. Services should be person centred and provide a range of interventions.

8. There is evidence that interventions, including communication groups, altering the environment and methods of stimulation and support provided by speech and language therapists is effective in reducing decline and improving quality of life.

9. Speech and language therapists have a key role in educating/training others involved in care of those with dementia and strategies to support communication.

10. Speech and language have a key role in training others involved in the care of those with dementia in strategies associated to improve the effectiveness and safety of feeding and swallowing.

11. Persons with dementia remain at risk as defined by The Incapacity Act and speech and language therapists are integral to assess incompetence for consenting.

12. Pathways of care for persons with dementia should integrate speech and language therapy and take account of the changing needs and focus of interventions as the condition alters and declines.

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Dementia Synthesis

The strategic objectives of the recently published National Dementia Strategy: Living Well with Dementia (Department of Health-11198) lists 17 objectives. Speech and language therapists can play a role in the implementation of many of these objectives by providing services as detailed within this document. Of particular note is the recognition of the importance of training and support for those employed to care for persons with dementia. There is guidance for commissioners contained within the National Dementia Strategy which details the requirement to provide locally led services, working with community partners, collaborating with clinicians and professionals and promoting innovation.

2. What is dementia?

The term dementia is used to describe a collection of symptoms, including a decline in memory, reasoning, and communication skills. It is recognised that swallowing problems occur in dementia, particularly in the later stages leading to practical, medical and ethical difficulties (NICE Dementia Guideline). Dementia is a progressive neurological disease which often results in total dependence. In most cases, supportive management of the person with dementia and their carers can reduce not only the burden of care but also additional morbidities. (Department of Health 282900/ Who cares? 2007).

All persons with dementia will have communication difficulties which are stressful to them and their relatives. The majority will experience swallowing problems during the course of the disease. Speech and language therapists have a unique role in identifying and analysing the specific nature of the speech and language impairment of persons with suspected or actual dementia. They can contribute to differential diagnosis and facilitate the identification of retained abilities and comorbidities (e.g. hearing loss).

3. How many people have dementia?

Studies show that the incidence of dementia rises with age. The prevalence rises from around 1% at age 65 to 35% at 85. The rate of increase for both genders is marked throughout ageing (Knapp et al, 2007a). It is estimated that 30% of those with dementia do not get a diagnosis, particularly in the young onset group (under 65 yrs) who are usually diagnosed later in the course of their dementia (Metcalf & Curtis, 2008). It is estimated that 75% of residents in care homes have dementia (Macdonald et al, 2002).

There are no known figures indicating the incidence of dementia in children.
Table 1: Incidence and prevalence figures of dementia

<table>
<thead>
<tr>
<th>Dementia in general population</th>
<th>Prevalence</th>
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</thead>
<tbody>
<tr>
<td>Incidence</td>
<td>Prevalence</td>
</tr>
<tr>
<td>163,000 UK with 15,000 &lt;65yrs</td>
<td>700,000 people in the UK</td>
</tr>
<tr>
<td>180,000 England and Wales (Matthews &amp; Brayne 2005)</td>
<td>40-65 yrs 1/1000 65-70 yrs 1/50 70-80 yrs 1/20 80+ yrs 1/5</td>
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<tr>
<td></td>
<td>1 in 5 &gt; 80 yrs 1 in 20 &gt; 65 yrs (Knapp et al 2007a)</td>
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<td></td>
<td>65-69 - 1.3 70-74 - 2.9 75-79 - 5.9 80-84 - 12.2 90-94 - 28.6</td>
</tr>
<tr>
<td></td>
<td>95 and over - 32.5 (Knapp et al 2007b)</td>
</tr>
<tr>
<td></td>
<td>7.4/1,000 person yrs (95% CI) age 65–69 yrs to 84.9/1000 person yrs (95% CI) ≥ 85 yrs (Matthews &amp; Brayne 2005)</td>
</tr>
</tbody>
</table>

4. What causes dementia?

There are many conditions that involve dementia (Dementia UK, 2007). Its greatest prevalence is in older adults though there are some rare conditions that result in dementia in children.

Of the different causes of dementia Alzheimer's disease accounts for approximately two thirds of the cases of dementia in the elderly and is related to changes in chemistry and structure of the brain. The Vascular dementias are caused by small vessel disease or strokes. Frontotemporal dementia is rarer, and predominantly effects the frontal lobes. It includes Pick's disease and primary progressive dysphasia, and often affects people under 65. It frequently has a greater impact upon the person's behaviour, communication and personality rather than memory. Lewy body dementia is caused by protein deposits developing inside nerve cells of the brain and interrupting normal functioning.

5. How does dementia affect individuals?

Dementia varies in its signs and symptoms relative to the type of dementia as chemical changes occur in the brain. This results in a slow, gradual loss of function characterised by loss of memory, mood changes and loss of communication. Two thirds of people with dementia are living in the community, supported by their families, with the demands and stresses of coping with this deteriorating condition. There are some 60,000 deaths a year that are directly attributable to dementia (Knapp et al, 2007).
### Table 2: Dementia and its associated features

<table>
<thead>
<tr>
<th>Type</th>
<th>Features</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Alzheimer's</strong></td>
<td>Gradual onset of memory loss</td>
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<tr>
<td></td>
<td>Difficulty finding words or using inappropriate words.</td>
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<td></td>
<td>Regularly misplacing everyday items, putting things in odd places, forgetting or denying action.</td>
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<tr>
<td></td>
<td>Problems with everyday tasks.</td>
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<td></td>
<td>General disorientation, not recognising familiar streets, confusion about the time of day.</td>
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<td></td>
<td>Diminished judgement, dressing inappropriately, being unaware of dangerous situations.</td>
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<tr>
<td></td>
<td>Mood or behavioural problems: may exhibit agitation, irritability, apathy, lack of care in personal hygiene.</td>
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<tr>
<td></td>
<td>Difficulties with swallowing</td>
</tr>
<tr>
<td><strong>Vascular dementia</strong></td>
<td>The symptoms reflect the area of the brain, which has reduced vascular supply or is affected by a stroke. Early symptoms are similar to those of Alzheimer's. However loss of function happens in distinct steps.</td>
</tr>
<tr>
<td><strong>Fronto-temporal dementia</strong></td>
<td>A rare condition, typically affects people in their 50s and 60s.</td>
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<tr>
<td>Pick's disease</td>
<td>Personality changes, such as a loss of inhibition, rudeness, apathy, impatience, or inappropriate behaviour of which the person is often unaware.</td>
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<tr>
<td>Primary Progressive Aphasia</td>
<td>Loss of emotional warmth and empathy for others, appearing selfish and unfeling.</td>
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<tr>
<td></td>
<td>Language decline may be the presenting symptoms</td>
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<td></td>
<td>A decline in language abilities, initially patients may have trouble remembering or understanding low frequency words and people’s names.</td>
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<tr>
<td></td>
<td>Overeating or changes in dietary preference, e.g. craving sweet foods.</td>
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<td></td>
<td>Changes in sexual behaviour.</td>
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<tr>
<td></td>
<td>Memory remains intact in the early stages while there is a decline in communication abilities giving the impression of memory problems.</td>
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<tr>
<td><strong>Lewy Body disease</strong></td>
<td>Confusion or delirium that fluctuates.</td>
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<td></td>
<td>Persistent hallucinations, usually involving an animate object in the same place.</td>
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<tr>
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<td>Paranoia</td>
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<td></td>
<td>Spontaneous Parkinson's disease-type symptoms, involving tremor or rigidity.</td>
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<td>Regular falls or a change in walking style.</td>
</tr>
</tbody>
</table>

Dementia can be seen as going through three stages progressing from mild, moderate to severe loss of function. Language can be affected at each stage causing difficulties in understanding and expression and may, along with memory problems, be an early indicator of the condition. Individuals may demonstrate word finding difficulties, particularly for objects and people’s names and use empty phrases (i.e without meaning). Additionally, the individual has difficulty in focusing on a topic of conversation and may start in the middle of a topic, with no reference to the listener’s knowledge or understanding of the subject. This difficulty in providing relevant information for the listener causes communication to break down and is frequently misunderstood by the communication partner (Feyereisen et al 2007, Carlomagno et al 2005).
Communication difficulties experienced

There is a broad range of communication difficulties experienced by the person with dementia and these will change during the course of the disorder. Specialised assessment will identify the specific psycholinguistic impairment which can assist in management. Amongst the communication difficulties experienced are:

- Repetition of topic or questions
- Paucity of speech
- Problems with turn-taking
- Reduction of non-verbal skills
- Inappropriate topic change or maintenance
- Confabulation or evidence of memory disturbance
- Reduction of speech Intelligibility, e.g. presence of dysarthria or apraxia
- Difficulty with sequencing
- Absence or inappropriate verbal reasoning
- Reduced comprehension
- Difficulty in maintaining focus in a conversation (or when watching television)
- Reading, writing and numeracy difficulties

Swallowing difficulties experienced

There is a risk of feeding and swallowing problems caused by neurological changes and altered cognitive abilities. Studies have reported a high incidence of dysphagia (eating and swallowing problems) with increased risk of aspiration pneumonia, nutritional compromise and in some instances death from malnutrition, choking and aspiration. Steele et al (1997) found an incidence of dysphagia in 68% of residents in a care home and in Horner et al. study (1994) aspiration was detected in 28.6% of individuals with a dementia with bronchopneumonia being a leading cause of death.

*Further information on the nature and management of swallowing disorders can be found in the accompanying synthesis on dysphagia*
## Table 3: International Classification of Functioning (ICF) dimension and impact of dementia

<table>
<thead>
<tr>
<th>ICF dimension</th>
<th>Impact</th>
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</table>
| Impairment    | Cognitive impairment –  
Attention and concentration  
Frontal lobe executive skills and reasoning  
Insight  
Memory - immediate, recent and long-term  
Mood, motivation and behaviour  
Orientation – time, place and person  
Perceptual and spatial disturbance  
Psychotic symptoms: auditory/visual hallucinations  
Registration, recall and recognition  
Sensory impairment  
Speech and Language impairment  
Numeracy  
*Psychological impairment* –  
psychosis  
Personality disorder  
Incidence or patterns of verbal or physical aggression  
*Physical impairment* –  
Eating and swallowing impairment  
Dyspraxia  
Progressively reduced co-ordination  
Progressively reduced power and range of movements |
| Activity      | Progressive loss of intelligible speech  
Progressive loss of ability to use language meaningfully  
Altered ability in feeding and drinking  
Progressive loss of ability to sequence tasks or use objects appropriately  
Development of inappropriate behaviours  
Increasing dependency on others  
Diminution of recent and new learning skills  
Progressive loss of life skills  
Reduced independence |
| Participation  | Loss of autonomy  
Restricted environment  
Social interaction  
Social participation |
| Well-being    | Frustration  
Anxiety  
Agitation  
Depression  
Mood changes  
Anger |
6. What are the aims/objectives of Speech and Language Therapy interventions for dementia?

The aims and objectives of specific interventions relate to maintaining and stimulating communication and take into account:

- the nature and severity of the dementia
- the communication needs of the individual
- the presence of an eating or swallowing disorder
- other factors relating to the person with dementia, such as medical co-morbidities, sensory impairment, socio-cultural factors
- factors relating to the environment, as it pertains to communication, where the person with dementia is living or staying
- the (training) needs of carers and/or the multi disciplinary team in relation to supporting any communication or swallowing intervention by the speech and language therapist

Speech and language therapists receive referrals of persons with altered communication in order for this to be assessed to assist with medical diagnosis. The Speech and Language Therapist aims to identify the nature and extent of the presenting difficulties in communication and swallowing by taking a full case history. This includes relevant medical information, aetiology, identifying the communicative environment and needs of the individual, their family situation, and family/carer’s needs. Objective psychometrically robust assessments will assist in the process of obtaining a differential diagnosis of the individual (i.e. between normal ageing and dementia; stroke and dementia; type of dementia; impact of medication etc). In addition, the progressive loss of understanding and competencies mean that spouses and family members change roles to one of carer.

An assessment of language and communicative abilities forms part of the evidence for determining mental capacity (Mental Capacity Act, 2005) and to support arrangements under Power of Attorney and Enduring Power of Attorney. This allows the carer to make decisions on behalf of the individual with dementia.

The focus of speech and language therapy interventions is to develop strategies to preserve communication skills and cognitive functioning for as long as possible. These strategies can include written cues for completing tasks or to assist memory recall, developing memory books including photographs and significant facts to help recall personal information, and in training family members or caregivers in how to communicate in a way which assists and includes the person with dementia.

SLTs adopt a number of approaches including multi-modality intervention, and exercises to help memory and language. Studies have shown that specific activities can help to preserve functional communication in some individuals. Activities include work on meaningful everyday vocabulary; keeping the individual to a routine, using familiar items to support recognition, enabling the person to follow activities that directly engage and maintain participation that is meaningful (Snowden et al 2006, Snowden 2005). It is suggested that encouraging and maintaining a variety of life experience appears to help to slow symptom progression for some people with dementia.
Adapting or altering the environment in order that it can provide more visual prompts to assist the person with dementia to interact appropriately and independently for longer can be facilitated by the speech and language therapist.

Dementia is a life changing disorder, which brings with it many psychological and social issues for the family and carer, as well as secondary complications due to communication, feeding and swallowing problems. Communication problems can also lead to heightened vulnerability. It is essential that these risks be minimised by access to a Speech and Language Therapist throughout the course of the dementia, involving regular review, and support for family and carers.

### 7. What is the management for dementia?

Speech and language therapists work within the multidisciplinary team to provide appropriate assessment, advice, education and support to individuals and their families as the dementia progresses. The SLT will aid the multidisciplinary team members in understanding and managing the communication needs of the individual. This will, in turn, facilitate functional and appropriate communication by all involved, contributing to the overall multidisciplinary intervention programme. There will be a need for ongoing intervention, the nature and intensity of which will vary as the abilities of the individual change and there is increased loss of function.

**Table 4 International Classification of Functioning (ICF) dimension: SLT intervention approaches in dementia**

<table>
<thead>
<tr>
<th>ICF dimension</th>
<th>Techniques</th>
</tr>
</thead>
</table>
| Impairment    | Stimulate speech and language  
Use strategies to improve memory  
Use cueing approaches to facilitate reading |
| Activity      | Help understanding and functional impact of communication difficulties  
Develop communication programmes for communication needs  
Develop strategies to facilitate functional communication  
Advise on feeding and swallowing  
Advise and strategies to sustain nutrition e.g. altered diet  
Develop use of communication strategies  
Develop use of assistive and augmentative communication |
| Participation | Providing education about dementia to patient, family and/or carer and advice on coping strategies and self-esteem.  
Advise on strategies to maintain social participation  
Advise on strategies to maintain social inclusion  
Advise on aspects of choice  
Advise of strategies to cope with challenging behaviour  
Provide information and evidence to support decisions surrounding mental capacity |
| Well-being    | Advise on strategies to reduce anxiety, frustration and upset |
National drivers are shaping the management of people with dementia: National Service Framework for Older People (Dept of Health, 2001), Everybody’s business (CSIP, 2005), NICE/SCIE Clinical Guideline on Dementia (NICE 2006), Dementia UK (2007). All these policy documents emphasise the need for integrated services and for seamless working across agencies. Multi-agency teams endeavour to contribute to the early diagnosis of individuals, provision of appropriate intervention and good quality information for those with dementia and their carers and provide on going support and advice. Speech and Language therapists work as part of these multidisciplinary teams, liaising with other team members in assessment, planning and maintenance of quality of life targets. They provide training and education on communication, swallowing and challenging behaviour strategies for the individual and their family, carers and care home workers to provide an holistic approach to care.

There are time implications for the education and training that SLTs provide to other professionals and family members. Working as part of a multidisciplinary team necessitates taking on team roles and attending meetings, which also have time implications.

Further information on the nature and management of swallowing disorders can be found in the accompanying synthesis on dysphagia

Augmented and Alternative Communication

Augmentative and Alternative Communication (AAC) refers to any system of communication that is used to supplement or replace speech, to help people with communication impairments to communicate. For individuals with dementia this could range from ‘low tech’ aids such as writing, picture charts or communication photo books, to ‘high tech’ aids such as technical sensors with vocal output which can act as a memory prompt.

The objectives of introducing AAC are to maximise the person with dementia functioning in the areas of life that need support and are seen as useful to the person and their communicative partner. The system will need to be continually reviewed to meet changing needs. Access to AAC services should be available for specialised assessment and provision of equipment

Cultural diversity

Individuals who use English as their second language and have a dementia, along with their families may need help to access services. An interpreter may be required to assist with conducting the SLT assessment to ensure it is both accurate and reliable and to facilitate understanding of therapy and implementation of treatment strategies. There are time and cost implications when working with interpreters/co-workers for example, in taking a case history, completing a full assessment in all languages spoken by the individual and their family. SLTs working with people with dementia need to be aware of cultural and religious factors which may impact on ability to access services, e.g. timings of services need to be culturally sensitive, for example, not offering appointment times which coincide with religious observations (Communicating Quality 3, 2006).
8. What is the evidence for SLT interventions for dementia?

Literature synthesis

The focus of the interventional synthesis within this briefing is to provide a synopsis on the effectiveness of speech and language therapy interventions for dementia.

Methodology

The interventional synthesis is not intended to be a full systematic review within the area of dementia. However, they draw upon systematic review techniques to ensure that the syntheses are developed according to systematic, explicit and reproducible methods. The intention of the syntheses is to consolidate articles which represent some of the best research in the area of dementia. The initial synthesis was completed in early 2009, with the update completed in May 2013.

Literature searching

Systematic literature searches were undertaken to identify a range of evidence for speech and language therapy interventions for dementia. The interventional syntheses do not attempt to consolidate all research within the topic area of dementia; rather they aim to present a careful selection of the most current research within that field. Therefore, the approach adopted for the literature search aims to reflect this in its systematic and explicit approach, whilst not being totally exhaustive.

Firstly, search terms were selected within the project team drawing on the expertise of four speech language professionals. This involved listing all possible synonyms describing the condition or population (e.g. dementia OR Alzheimer’s disease) and combining those with terms described speech and language therapy. For the update of the synthesis the intervention terms were broadened to ensure that relevant research on challenging behaviour, communication and problems with eating were Terms were used in both free text and thesaurus searching. The following databases were used:

- ASSIA
- CINAHL
- The Cochrane Library (which includes the Cochrane Database of Systematic Reviews, Cochrane Central Register of Controlled trials, Database of Abstracts of Reviews of Effects, Health Technology Assessment Database and NHS Economic Evaluations Database).
- Linguistics and Language Behaviour Abstracts
- MEDLINE
- PsycINFO

All references retrieved from the literature searches were entered onto a Reference Manager Version 11 database using appropriate keywords.

The searches results were limited to English Language and to studies after 1998.
Selecting and obtaining relevant articles

Articles for inclusion were selected to illustrate the range of good quality evidence within each topic area. An initial screening of articles was undertaken by Anna Cantrell who adopted the following principles:

- Articles must be empirical research evaluating the effectiveness of a particular speech and language therapy intervention
- Only articles published in English language are included.
- In general, only the most current (1998-present) literature is included. However, exceptions were made to this if a particular article was felt to be important to include.
- Where possible higher level evidence was included (systematic reviews, randomised controlled trials). However, this research did not always exist necessitating the inclusion of lower levels of evidence i.e. case series, pilot studies and cohort studies. Additionally, effort was made to seek out literature that provided a range of perspectives on interventions for each topic area, i.e. both quantitative and qualitative research.

Following initial screening, the remaining articles were examined by Pam Enderby who has considerable speech and language therapy knowledge and experience.

Assessing the quality of relevant articles

Formal quality assessment of the articles was not undertaken. Instead, quality assessment involved using checklists as a guideline to give an indication of the overall quality of studies and identify the main errors within each study. For each interventional synthesis, the study designs are listed and the problems with each study design noted. Common errors within the studies are noted and general observations on study quality are made. The checklists used are one for quantitative and one for qualitative studies from the Alberta Heritage Foundation for Medical Research (2004). Additionally, when an identifiable study design was used, the appropriate Critical Appraisal Skills Programme (n.d.) checklist was selected. Where, studies met all quality indicators on the appropriate checklist, they were deemed excellent. Good studies generally had two to three faults identified by the quality checklists and average studies had more than three faults identified. ‘Faults’ depended on the study design being assessed. For example, in a randomised controlled trial, failure to explain the randomisation procedure or numbers lost to follow up during the trial could affect the robustness of the study outcomes and hence the quality of the study. For more information about faults in different study design, please look at the quality checklists used within these briefings.
## Dementia Synthesis

<table>
<thead>
<tr>
<th>Study</th>
<th>Country</th>
<th>Study Design</th>
<th>Subjects</th>
<th>Intervention</th>
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<tbody>
<tr>
<td>Arkin, S. and Mahendra, N. and Arkin, S. (2003)</td>
<td>USA</td>
<td>Clinical trial</td>
<td>24 patients with mild to moderate Alzheimer's Disease. Mean age 78.8 years, range 54-88 years. 67% female, 33% male.</td>
<td>Undergraduate students administered an intervention of communication skills practice, fitness training and supervised volunteer work for 10 week per semester. Programme provided over 4 year period.</td>
</tr>
<tr>
<td>Arkin, S. And Mahendra, N. (2001)</td>
<td>USA</td>
<td>Pilot study</td>
<td>11 Alzheimer's Disease patients. 7 in experimental and 4 in comparison group. Mean age in comparison group 82.4 years, mean age in experimental group 75.7 years.</td>
<td>In the first semester all participants received 20 physical fitness workout session – two each week for 10 weeks. In the second semester a 60-minute session of community volunteer work was added. The experimental group also received a language intervention administered once per week for 10 weeks.</td>
</tr>
<tr>
<td>Brodaty, H. and Arasaratnam, C. (2012)</td>
<td>Worldwide</td>
<td>Systematic Review</td>
<td>23 studies including 3279 dyads; caregivers and patients with dementia.</td>
<td>Nonpharmacological interventions for neuropsychiatric symptoms of dementia. Interventions included in review were categorised into 6 types: skills training for caregivers, education for caregivers, activity planning and environmental redesign, enhancing support for caregivers, self-care techniques for caregivers and miscellaneous.</td>
</tr>
<tr>
<td>Broughton, M. et al (2011)</td>
<td>Australia</td>
<td>Clinical Trial</td>
<td>68 care staff in four nursing homes with a specific unit for patients with dementia.</td>
<td>Care staff received a DVD-based training programme called RECAPS and MESSAGE. The programme aimed to provide staff with strategies for supporting memory and communication in people with dementia.</td>
</tr>
<tr>
<td>Burgio, L.D. et al (2001)</td>
<td>USA</td>
<td>Randomised Controlled Trial</td>
<td>64 certified nursing assistants working with nursing home residents some with moderate cognitive impairment. 37 were in the intervention group and had a mean age of 39.30 years and 25 were in the comparison group with a mean age of 35.13 years.</td>
<td>Nursing assistants were taught to use communication skills and memory books in their interactions with residents. A staff motivational system was used to encourage performance and maintenance of these skills. The comparison group received no intervention.</td>
</tr>
<tr>
<td>Study</td>
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<tr>
<td>de Rotrou, J. et al (2011)</td>
<td>France</td>
<td>Randomised Controlled Trial</td>
<td>167 patient-caregiver dyads. Patients had mild to moderate Alzheimer’s disease.</td>
<td>Caregivers attended a psycho-educational programme or received usual care. The programme was delivered in 12 group sessions of 2 hours over a 3 month period.</td>
</tr>
<tr>
<td>Dijksra, K. et al (2002)</td>
<td>USA</td>
<td>Clinical Trial</td>
<td>40 nursing assistants working with 66 nursing home residents with a dementia diagnosis. Patients were early middle or late stage dementia. Nursing assistants had an average age of 36 years, were mostly female and mostly African-American.</td>
<td>Nursing assistants in the intervention group received communication training consisting of 1-hour in-service training and 2-4 week hands-on training during care routines. The comparison group received no intervention.</td>
</tr>
<tr>
<td>Done, D.J. and Thomas, J.A. (2001)</td>
<td>UK</td>
<td>Clinical Trial</td>
<td>45 carers of people suffering from dementia</td>
<td>Participants attended a workshop or received a booklet. The workshop group attended a communication workshop which consisted of 2 sessions of 1 hour each delivered by a specialist speech and language therapist. The booklet group received a booklet about improving communication.</td>
</tr>
<tr>
<td>Egan, M. et al (2010)</td>
<td>Worldwide</td>
<td>Systematic Review</td>
<td>13 studies of patients with dementia (including at least 50% of the study population with a diagnosis of Alzheimer’s disease) and their caregivers.</td>
<td>The review investigated the effectiveness of interventions to enhance verbal communication for people with dementia diseases and their caregivers. There were 8 studies on memory books with caregiver training, 3 on education and training programmes and 2 on activity-based programmes.</td>
</tr>
<tr>
<td>Eggenberger, E. et al (2012)</td>
<td>Worldwide</td>
<td>Systematic Review</td>
<td>12 clinical trials including 831 people with dementia, 519 professional caregivers and 162 family caregivers.</td>
<td>This review investigated communication skills training in dementia care. 8 studies were based in nursing homes and 4 in home-care settings.</td>
</tr>
<tr>
<td>Fritsch, T. et al (2009)</td>
<td>USA</td>
<td>Clinical trial</td>
<td>Nursing home residents with dementia and their caregivers on 20 nursing home facilities in 2 states. Residents had middle to late-stage dementia.</td>
<td>TimeSlips, a group storytelling programme was introduced in 10 homes over a 10 week period. Groups of 10-12 residents met weekly for about 1 hour.</td>
</tr>
<tr>
<td>Haberstroh, J. et al (2011)</td>
<td>Germany</td>
<td>Clinical trial</td>
<td>22 informal caregivers of people with dementia. People suffered from Alzheimer’s disease, vascular dementia and dementia of mixed etiology.</td>
<td>TANDEM communication training a psychosocial programmes that focuses on communication in dementia care. Caregivers attended weekly sessions of 2 and 1/2 hours for 5 weeks.</td>
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<td>Study</td>
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<td>dementia or an unspecified progressive dementia. Age range 52-96.</td>
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<tr>
<td>Jelicic,N. Et al (2012)</td>
<td>Italy</td>
<td>Randomised Controlled Trial</td>
<td>40 patients with mild memory decline and a diagnosis of probable Alzheimer’s disease.</td>
<td>Participants received lexical-semantic stimulation or unstructured cognitive stimulation. Sessions were twice a week for 1 hour for a period of 3 months.</td>
</tr>
<tr>
<td>Klodnicka Kouri, K. et al (2011)</td>
<td>Canada</td>
<td>Clinical Trial</td>
<td>Fifty caregivers of a family member or friend diagnosed cognitive problems associated with early stage of probable Alzheimer’s disease.</td>
<td>Psycho-educational intervention on communication for caregivers. The intervention was delivered in weekly sessions lasting 90 to 120 minutes for five weeks. In the control group caregivers received an information flier on communication and memory.</td>
</tr>
<tr>
<td>Liddle, J. Et al (2012)</td>
<td>Australia</td>
<td>Randomised Controlled Trial</td>
<td>29 dyads of people with dementia and their informal caregivers. All dyads were living in the community.</td>
<td>Caregivers participated in two training sessions based on communication support strategies lasting for 45 minutes. The training sessions each introduced a training DVD of MESSAGE and RECAPS. The sessions were run by researcher with psychology or speech pathology qualification.</td>
</tr>
<tr>
<td>Logsdon, R. G. Et al (2010)</td>
<td>USA</td>
<td>Randomised Controlled Trial</td>
<td>142 dyads of patients with early dementia and their care partner.</td>
<td>Participants were randomised to attend an early-stage memory loss (ESML) support group or were placed on a waiting list. The EMSL intervention is a support group programme following a manual. Sessions typical last for 90 minutes and were weekly for 9 weeks.</td>
</tr>
<tr>
<td>Study</td>
<td>Country</td>
<td>Study Design</td>
<td>Subjects</td>
<td>Intervention</td>
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</tr>
<tr>
<td>Mahendra, N. Et al (2005)</td>
<td>Worldwide</td>
<td>Systematic Review</td>
<td>3 studies including 24 participants, 17 with Alzheimer’s Disease (11 women and 6 men) and 7 as comparison in 3 studies. Age range 49-90 years.</td>
<td>Computer-assisted cognitive interventions.</td>
</tr>
<tr>
<td>Mattos Pimenta Parente, M. A. D. Et al (2004)</td>
<td>Brazil</td>
<td>Clinical Trial</td>
<td>49 subjects, 16 with mild or probable Alzheimer’s disease, 18 elderly without significant memory complaints and 15 college students. Mean age 71.87, 74.83 and 27.93 respectively.</td>
<td>Each participant worked through a linear and hypertext story on the computer and was then assessed on how much of the story they remembered.</td>
</tr>
<tr>
<td>Murphy, J. and Oliver, T. (2013)</td>
<td>UK – Scotland and Northern England</td>
<td>Clinical trial</td>
<td>Eighteen couples comprising people with dementia and their family carers. 3 participants had early stage dementia, 13 moderate stage and 2 late stage.</td>
<td>Use of the Talking Mats framework in decisions about daily living between people with dementia and their family carers. Talking Mats is a simple system of picture symbols on a textured mat that allows people to show their feelings about different options for a specific topic. Topics in this study were personal care, getting around, housework and activities.</td>
</tr>
<tr>
<td>Noonan, K.A. et al (2012)</td>
<td>UK</td>
<td>Case series</td>
<td>8 patients suffering from anomia with a clinical diagnosis of probable Alzheimer’s disease.</td>
<td>Patients attended errorless or errorful therapy. Sessions were run twice a week for five weeks. Therapy was tailored for each participant.</td>
</tr>
<tr>
<td>Ousset, P.J. et al (2002)</td>
<td>France</td>
<td>Randomised Controlled Trial</td>
<td>16 mild Alzheimer’s disease patients with anomia. In lexical therapy group 5 men and 3 women, mean age 67.7 years. In occupational programme group 3 men and 5 women mean age 73.8 years.</td>
<td>8 subjects attended lexical therapy sessions lasting 45 minutes for 5 months. 8 patients attended an occupational programme which consisted of sessions of drawing, pottery and conversation for same time and duration.</td>
</tr>
<tr>
<td>Ramstrom, I. (2011)</td>
<td>Sweden</td>
<td>Pilot study</td>
<td>5 patients with mild to moderate impairment probable Alzheimer’s disease</td>
<td>Language training entitled Stimulation Activation Training programme including use of a personal computer system. The programme was tailored to each patient and lasted for 12 months.</td>
</tr>
<tr>
<td>Study</td>
<td>Country</td>
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<tr>
<td>Reilly, J. et al (2005)</td>
<td>USA</td>
<td>Case series</td>
<td>5 patients with moderate to advance semantic dementia and anomia. 4 men and 1 woman. Age range 54-76 years.</td>
<td>2 experiments on the effects of repetition priming on word retention.</td>
</tr>
<tr>
<td>Ripich, D. N. et al (1999)</td>
<td>USA</td>
<td>Clinical Trial</td>
<td>54 Alzheimer’s Disease caregivers. Mean age of FOCUSED group was 61.9 years, FOCUSED Booster group was 63.2 years and comparison group was 62.3 years.</td>
<td>22 participants in FOCUSED group received FOCUSED communication training which consisted of 8 hours of training spread over 4 weekly group sessions. 10 participants in the FOCUSED Booster group receive FOCUSED communication training and additional follow-up training tapes and phone calls. 22 participants served as a comparison group and received no intervention.</td>
</tr>
<tr>
<td>Santo Pietro, M. J. And Boczko, F. (1998)</td>
<td>USA</td>
<td>Clinical Trial</td>
<td>40 nursing home residents with mid-stage Alzheimer’s disease. Age range 75-100 years.</td>
<td>20 residents attended breakfast club in groups of 5, 5 days a week for 12 weeks. 20 residents participated in short conversation group in groups of 5, 5 days a week for 12 weeks.</td>
</tr>
<tr>
<td>Senaha, M.L.H. et al (2010)</td>
<td>Brazil</td>
<td>Case Series</td>
<td>3 patients with semantic dementia.</td>
<td>Cognitive-linguistic rehabilitation for lexical reacquisition based on errorless learning. Patients were treated individually and the selection of words was tailored to each patient. Sessions were twice a week and patients were also instructed to train at home. The length of the training differed for each patient.</td>
</tr>
<tr>
<td>Tappen, R. M. et al (2001)</td>
<td>USA</td>
<td>Randomised Controlled Trial</td>
<td>55 nursing home residents with Alzheimer’s disease. 87% female. Mean age 87 years, range 71-101 years.</td>
<td>Participants were assigned to a conversation treatment group, assisted walking group or a combined conversation and walking treatment group. All treatments provided in 30 minute sessions three times a week for 16 weeks.</td>
</tr>
<tr>
<td>Study</td>
<td>Country</td>
<td>Study Design</td>
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<tr>
<td>Woods, R.T. et al (2012)</td>
<td>UK</td>
<td>Randomised Controlled Trial</td>
<td>350 dyads of individuals with mild to moderate dementia and a family or informal carer.</td>
<td>Reminiscence groups were attended by people with dementia and their family carers weekly for 12 weeks then further monthly maintenance sessions for 12 months.</td>
</tr>
<tr>
<td>Zientz, J. et al (2007a)</td>
<td>Worldwide</td>
<td>Systematic Review</td>
<td>Caregivers of patients with Alzheimer’s Disease.</td>
<td>Educating caregivers about Alzheimer’s Disease and training them to use communication strategies to enhance communication effectiveness.</td>
</tr>
<tr>
<td>Zientz, J. et al (2007b)</td>
<td>Worldwide</td>
<td>Systematic Review</td>
<td>152 patient career dyads in three studies. Patients had Alzheimer’s Disease. Average age of caregivers 68 years, patients 71 years. 72% of caregivers and 34% of patients were female.</td>
<td>Cognitive stimulation therapy administered by caregivers.</td>
</tr>
</tbody>
</table>

**Syntheses of the articles**

Each article was read in turn by Anna Cantrell. The key points were summarised including the objective of the study, the participants’ characteristics, the methodology, the intervention, results and limitations. From this, articles were grouped into themes according to the type of intervention being investigated (e.g. swallowing therapy, diet modification). Results were summarised and drawn together within each particular theme and a summary paragraph provided at the end.

**Studies**

All studies were published in English, with the earliest being published in 1998. The majority of the studies (13) were conducted in USA, 3 in the UK, 2 in France, 2 in Brazil, 2 in Australia, 2 in Canada and 1 in Italy and Sweden. 13 of the studies synthesised results from studies worldwide. 11 of these were systematic reviews and the other two were literature reviews. The number of individuals who took part in the studies ranged from 3 to 731. The included studies investigated interventions for patients with mild to moderate dementia with all studies using validated measures to assess the degree of dementia. Interventions were either directly delivered to the patients with dementia or delivered to their caregivers – family members or nursing home staff. Interventions were to improve or maintain patient’s cognitive status, their language communication skills or their functioning. Two
of the studies were surveys of speech-language pathologists in USA to determine their knowledge and practices related to tube feeding in patients suffering from dementia.

Study design

The synthesis includes studies with a range of study designs. There were 8 randomised controlled trials, 12 clinical trials, 12 systematic reviews, 2 reviews, 3 case-series studies, 2 pilot studies, 2 surveys and 1 observational study. The quality of the eleven systematic reviews was generally very good to excellent. The randomised controlled trials were of fair to good quality with their strength being in good statistical analysis of results and the consideration of confounding factors. Common errors included no details of the randomisation process and small numbers participating in the study. Caution should be applied if generalising results from small studies to the larger population of dementia patients. Similarly the clinical trials and pilot studies had small numbers participating and in some self-selection to take part in the studies. The lack of randomisation in the clinical trials introduces the possibility of bias. Results from case studies have been included in this synthesis. However, it is important to be aware that they provide weaker evidence of effectiveness of interventions. The quality of the two literature reviews was poor as they provided no information about their methodology.

Finally, it is worth noting that the findings from the non-UK papers need to be interpreted cautiously due to generalisability of findings to the UK population.

Direct Interventions

A number of the studies investigated direct interventions for patients with dementia. Interventions were delivered to the patient with dementia by speech language therapists, other medical professionals, students and carers. Direct interventions included spaced retrieval training, errorless learning and multi-sensory interventions.

One systematic and one literature review reviewed the evidence on different interventions to improve communication between people with dementia and their carers.

A good systematic review (Egan, M. et al 2010) focused on the evidence of different interventions to improve verbal communication between people with dementia and their carers. Formal or informal carers were included. The review included 13 studies categorised into memory books and caregiver training, education and training programmes and activity based programmes. There were 8 studies on memory books including the RCT by Burgio, L.D. et al (2001) which is discussed in more detail below. Three studies on education and training programmes were included and 2 studies on activity based programmes including a clinical trial on breakfast clubs (Santo Pietro, M. J. and Boczko, F. 1998) which is discussed further below. The review found only one technique, the use of memory aids combined with specific caregiver training programmes, to be possibly beneficial. Included studies had limitations relating to their methodology which meant that the strength of the recommendations was limited. Limitations included small sample size, non-random allocation of participants to study groups, no control group and non-blinding of study personnel measuring outcomes. Further high-quality research into these interventions would be beneficial.
The literature review (Mahendra, N. 2001) reviewed the different direct interventions to improve the communication and functioning of patients with Alzheimer's disease. The review covered spaced retrieval training (SRT), errorless learning, quizzes, using multisensory stimuli, use of memory wallets and book, use of personal computers, cognitive-linguistic stimulation programmes and the Montessori approach. The review found considerable evidence that cognitive-linguistic therapy benefits individuals with Alzheimer's disease by strengthening existing associations and building new ones. The review also found promising future directions in clinical interventions including combining approaches such as SRT and errorless learning and the use of meaningful sensory stimuli to provide more patient therapy and make learning easier and more efficient for individuals with Alzheimer's disease. The majority of direct interventions research was conducted with mild to moderate Alzheimer's disease therefore the interventions may be less successful or need to be appropriately modified for patients with severe disease.

Language therapy

Eight studies considered the impact of language therapy on patients with dementia.

One small RCT (Ousset, P.J. et al 2002) conducted in France investigated the effects of language therapy for a group of 16 patients with anomia in mild Alzheimer's disease. The 8 participants in the lexical therapy group received therapy which consisted of a sequence of 8 written narratives presented on computer screen and read aloud by study participant and then the examiner. Within the narratives 20 definitions were presented. The comparison group received an occupational programme which consisted of sessions of drawing, pottery and conversation conducted for the same time. After the intervention, the lexical therapy group performed better on a naming test, using words and definitions from the narratives, than the comparison group whose performance decreased. This study indicates that a group of Alzheimer's disease patients can benefit to some extent from language therapy specifically for anomia.

Another RCT (Jelcic, N. et al 2012) investigated the effectiveness of lexical-semantic stimulation on episodic memory and verbal communication in patients with mild memory decline in Italy. Patients received lexical-semantic stimulation or unstructured cognitive stimulation in twice weekly sessions for 3 months. The study found the lexical semantic stimulation was effective and that the cognitive improvement was retained at 6 months post-therapy. This study suggests that lexical semantic stimulation might be an effective intervention to slow cognitive decline in the early stages of dementia.

A small case series (Reilly, J. et al 2005) investigated the effect of repetition priming on word retention in individuals with moderate to severe semantic dementia with anomia. The study results indicate that repetition priming alone is unlikely to be an effective strategy for reacquisition of forgotten vocabulary in patients with semantic dementia. However, the study demonstrated that some individuals with semantic dementia continue to benefit from language support in word list recall and that it would perhaps be a useful strategy for maintenance of vocabulary using sets of personally relevant words. The authors conclude that the severity of semantic dementia may impact on the effect of repetition priming on word reacquisition or retention.

A small clinical trial (Mattos Pimenta Parente, M.A.D. et al 2004) investigated whether patients with Alzheimer's disease had improved textual recall when reading in a hypertext format. The textual
recall of 16 patients with a probable diagnosis of Alzheimer’s disease were compared with 18 elderly patients without significant memory complaints and 15 college students. Participants read a narrative on a computer in a linear or hypertext format and were then assessed on their recall. The patients with dementing disease had lower performance in both stories than those of the two healthy groups. In comparison with the other groups they benefited most from the hypertext format. The findings from this study suggest that hypertext could be used as tool to help patients with Alzheimer’s disease overcome problems in text comprehension.

An intervention study (Fritsch, T. et al 2009) introduced TimeSlips, a group storytelling programme, to residents with dementia in nursing homes in America. TimeSlips aimed to encourage creative expression among people with dementia and their carers. Sessions were facilitated by nurses’ aides, social workers and/or activity directors. The observations of the residents in the intervention group showed that residents were more alert and engaged when compared with observations of the control group. In TimeSlips nursing homes more frequent staff-resident interactions, social interactions and social engagement were observed. However, observations only occurred after the intervention making it impossible to determine how much change had occurred over time. The staff who had participated in TimeSlips had more positive opinions of residents with dementia although there were no differences in their job satisfaction or levels of exhaustion as compared with staff in the control nursing homes. This study provides promising evidence for TimeSlips indicating that further research, using more robust methodology, on this intervention would be useful.

A recent pilot study (Ramstrom, I. 2011) conducted in Sweden investigated a language training programme for five patients with mild-to-moderate dementia disease that included the use of a personal computer. The programme lasted 12 months and the language training consisted of a Stimulation-Activation-Training-Programme which included pragmatic, semantic, writing, conversation and counting sessions. In addition to paper based tasks a computer with exercise programmes was used. The five patients’ linguistic competence was assessed using a standardised assessment tool at the start and end of the programme. All five patients were able and happy to use the computer system. At the end of the study the patients’ linguistic competence was preserved or slightly changed. The results from this pilot study indicate that the training programme might be helpful for patients with mild or moderate dementing disease.

A small case series conducted in the UK (Noonan, K.A. et al 2012) compared the effectiveness of errorless and errorful therapy for 8 patients with dementia and pronounced anomia. The therapy aimed to help the patients relearn the names of familiar objects with the list of objects tailored for each patient. The sessions of errorless and errorful approaches were both run twice a week for five weeks. The study found both techniques to be equally effective and concluded that either errorful or errorless learning could be used to help patients with anomia to relearn commons words. A further small case series (Senaha, M. et al 2010) considered the effectiveness of training based on principles of errorless learning on lexical reacquisition in 3 people with semantic dementia. Therapy was personalised for each patient. All patients performed better on naming treated items after the intervention however, there was decline in naming of untreated items. The study concluded that the treatment might help patients regain lost vocabulary and that reacquisition might be possible in patients with semantic dementia.
The findings from the above studies suggest that language therapy in various forms could help people with dementia retain their linguistic competence, relearn words and improve their communication with their carers.

**Multi-modality intervention programmes**

Five of the interventions were multi-modality programmes which combined communication or language therapy with exercise, volunteer work or social activities.

A good RCT (Tappen, R. M. et al 2001) investigated the effectiveness of a conversation intervention in improving the verbal communication of nursing home residents with Alzheimer’s diseases compared with an exercise intervention and a combination of both. Differences between the groups were not significant. The conversation only group was found to be the most effective approach in improving communication performance. Many of the patients were frail and needed assistance with walking meaning it was difficult for patients in the combined group to be involved in conversation.

An RCT (Logsdon, R. et al 2010), conducted in America, investigated ESML support groups run by a local Alzheimer’s Association chapter. Individuals with early-stage dementia and their carer attended a group session weekly for 9 weeks with sessions lasting approximately 90 minutes. Carers and people with dementia met together for part of the session and then separately for other parts. The EMSL intervention is a structured programme following a manual with sessions facilitated by 3-4 volunteer facilitators who participated in ongoing training on delivering the intervention. Individuals who attended the groups were compared with individuals with dementia who joined a waiting-list control and were then offered the opportunity to attend the groups after all assessments had been completed. The study found that patients in the support groups had significantly better quality of life, less depression and better family communication than in the control group. No significant differences were found between the caregivers in each group. This study demonstrates that ESML support groups could be a useful intervention for individuals with early-stage dementia. However, care partners didn’t report that their quality of life improved and other interventions focused to their needs could be more beneficial for them.

A clinical trial, described in two papers (Arkin, S. 2007 and Mahendra, N. and Arkin, S. 2003), assessed the impact of cognitive-linguistic intervention programme, administered by students, on individuals with mild to moderate Alzheimer’s disease. The intervention had an exercise, language and social aspect to the intervention. Individuals attended for 10 weeks in a semester and the study ran for 8 semesters over 2 years. 24 individuals attended the programme with four completing the full four years. Significant annual decline in mental status occurred for all cohorts except participants that completed the full four years. Participants that completed two or more years maintained their cognitive function. All four of the 4 year completers were at the same stage of dementia as when they started the study. The results from the study were compared with data from CERAD, a large study of Alzheimer’s disease patients. Participants that attended one year had similar data. Following that point the data started to diverge with the most striking difference being between years 3 and 4 when the CERAD group declined much more than the participants in the programme. The findings from this small clinical trial suggest that an intervention that includes language, social and fitness aspect can help patients maintain or improve their cognitive function reducing their decline. The data from the four participants provided preliminary evidence that a long-term intervention
combining physical activity, language and social aspects can maintain or improve aspects of language performance in individuals with a progressive dementia.

A small pilot study (Arkin and Mahendra, 2001) investigated the impact of a multi-modality intervention programme on patients with mild or early moderate stage Alzheimer’s disease. Participants were allocated to an experimental or comparison group. All participants attended twice weekly physical fitness training and a weekly session of supervised volunteer work. Participants in the experimental group also received exercises for memory and language stimulation during their fitness workout. Participants in the comparison group just experienced unstructured conversation. The experimental group performed significantly better on the mental status measure and on the ratio of different nouns to total nouns and then similarly on the other outcome measures which included ratio of topic comments to total utterances, ratio of vague nouns to total nouns and picture description task. The findings suggest that a programme incorporating exercise and volunteer work can help Alzheimer’s disease patients to maintain their function.

A case-control study (Santo Pietro, M. J. and Boczko, F. 1998) examined the effectiveness of a breakfast club for nursing home patients with mid-stage Alzheimer’s disease. The impact of the breakfast club on their communication was compared with a group who attended a standard conversation group. Patients attended the Breakfast Club in small groups on week days for 12 weeks. The Breakfast Club participants improved significantly on measures of language, performance, functional independence and use of social communication which the comparison group did not. Members of the Breakfast Club also showed increases in “interest and involvement” and the use of procedural memory. The positive findings from this study support previous research demonstrating that a home-like environment with food stimuli, ample positive reinforcement and group therapy tasks can have a positive impact on the communication of patients with Alzheimer’s disease.

The findings from the above studies suggest that multi-modality intervention programmes can help patients with mild to moderate-stage dementia to improve or maintain their language, communication and functioning.

**Spaced retrieval training**

A systematic review (Hopper, T. et al. 2005) reviewed the evidence for the effectiveness of spaced retrieval training (SRT) for individuals with dementia, predominantly those with Alzheimer’s disease. The review found 15 studies of SRT which varied with regard to the types of associations, trained format of the spaced retrieval training and the dose-response characteristic of the treatment. The associations trained were generally cue-behaviour and face/object-name association. The results of the studies were overwhelmingly positive but the methodological shortcomings of the included studies warrant cautious interpretation of the findings.

**Computer-based interventions**

One systematic review and three trials considered computer-based interventions for patients with dementia.
A systematic review (Mahendra, N. et al 2005) reviewed the evidence for the effectiveness of computer-assisted cognitive interventions on patients with dementia, predominantly Alzheimer’s disease. The review included three studies which varied in the type of computer programme used, the format of the intervention and the specific task being trained. The findings from the studies suggest that Alzheimer’s disease patients with mild to moderate dementia can participate in computer-assisted cognitive interventions. Across the studies, participants showed improvement in performing specific tasks trained using a computer, methodological concerns about the included studies mean that the findings should be treated with caution. Additionally an RCT (Ousset, P.J. et al 2002), clinical trial (Mattos Pimenta Parente, M.A.D. et al 2004) and pilot study (Ramstrom, I. 2011) discussed in previous section all investigated computer-based interventions. The findings of the three studies were positive and participants found the use of the computer acceptable. The findings from these studies suggest that patients with dementia could interact with interventions provided on a computer.

**Reminiscence therapy**

Reminiscence therapy is becoming popular and involves an individual with dementia discussing past activities with another person or a group of people. Prompts such as photographs and music are used to evoke memories. One systematic review and one RCT investigated reminiscence therapy.

An excellent systematic review (Woods, B. 2009) considered the effects of reminiscence therapy for individuals with dementia. The review considered its effects on mood, cognition and well-being for people with dementia and their caregivers who are increasingly involved in reminiscence therapy. The review included five trials, synthesising the results from the four with extractable data. The included studies were small, of poor quality and all investigated different types of reminiscence therapy making comparisons difficult. Combining the studies found some promising indications of effectiveness in improving cognition and mood and caregiver’s involved in the therapy showed less strain. The results of the studies were positive but the small number and methodological shortcomings of the included studies warrant cautious interpretation of the findings.

A very good RCT (Wood, R.T. et al 2012) investigated the clinical and cost effectiveness of reminiscence groups for people with dementia and their caregivers in Bangor, Bradford, London, Manchester, Newport and Hull. Patient and caregiver dyads attended joint reminiscence groups weekly for 12 weeks. This was followed by maintenance sessions on a monthly basis for 7 months. The trial didn’t demonstrate that reminiscence therapy groups were clinically or cost effective. The authors caution that people with dementia might benefit from attending sessions but this must be considered in terms of whether it adds to their carer’s burden. Exploring the results from this study further could discover the differences between the effects on people with dementia and their caregivers and potentially consider if joint interventions are the way forward.

**Non-pharmacological interventions**

Three systematic reviews investigated the effectiveness of nonpharmacological interventions.

A systematic review (Kong, E.H. et al 2009) reviewed studies on the effectiveness of nonpharmacological intervention to reduce agitation in older adults with dementia. The systematic
review which includes a meta-analysis synthesised evidence from studies published in English and Korean. Fourteen studies selected as relevant for the review were organised into 7 types of interventions: sensory intervention, social contact, activities, environmental modification, caregiver training, combination therapy and behavioural therapy. Only sensory interventions, which included aromatherapy, thermal bath and calming music and hand massage, were found to be potentially effective in reducing agitation. The results of the systematic review should be considered with caution due to the small number of studies, small sample size and variability in measures used to assess agitation. Further research studies following more rigorous methods to enable stronger conclusion of the effectiveness of interventions to be drawn should be conducted. A later systematic review (Brodaty, H. and Arasaratnam, C. 2012) including meta-analysis investigated the effectiveness of nonpharmacological interventions delivered by family caregivers in a community setting on the management of behavioural and psychological symptoms of dementia. The review included 23 studies that were RCTs or pseudo randomised clinical trials. Interventions were found to be effective in reducing behavioural and psychological symptoms associated with dementia. The interventions that were effective were tailored to the person with dementia and their caregiver, included 9-12 sessions over 3-6 month period, were delivered in the home using multiple components. Many of the studies interventions comprised multiple components making it difficult to identify which aspect of the intervention improved symptoms. Additionally, the sample sizes investigated and the methodological quality of the studies varied weakening the strength of any recommendations.

Another good recent systematic review (Carthey-Gouler, et al 2013) focused on nonpharmacological interventions for cognitive impairments for patients with primary progressive aphasia. The study aimed to provide recommendations for clinical practice in this area. All of the 39 reviewed trials showed positive results however the methodological quality of included studies was low apart from 1 non-randomised case-control investigation all of the included studies were case-studies of one or more patients. Weak recommendations could be made for therapy aimed at naming and lexical retrieval and treatment aimed at object use. The 39 included studies investigated a total of only 67 patients indicating the small sample sizes of the included studies. Further research using more robust methodology would be useful in this area with research collaboration one possible method to achieve this.

Indirect Interventions

Fourteen of the studies investigated indirect interventions for patients with dementia. In these the interventions are administered to the patients caregiver; partner, family member or nursing staff in residential homes. All of these interventions were to improve carers knowledge of dementia and to improve the communication interactions of patients suffering from dementia and their carers through communications skills training for the patients caregivers.

A systematic review (Zientz, J. et al 2007a) reviewed the evidence for the effectiveness of educating caregivers on Alzheimer’s disease and communication strategies on their interactions with their patients with Alzheimer’s disease. Six studies were reviewed that supported the education and communication training of family and professional carers of individuals with Alzheimer’s disease. Methodological concerns with the included studies related to internal and external validity and dose response characteristics. Findings from the included studies support education and training in communication strategies for carers of individuals with dementia.
A later good systematic review (Egan, M. et al 2010), discussed in a previous section, reviewed the evidence on different interventions to improve verbal communication between people with dementia and their carers and found only one technique, use of memory aids combined with specific caregiver training programmes, to be possibly beneficial. The methodological shortcomings of the included studies warrant cautious interpretation of the findings. Included in this systematic review is an RCT (Burgio, L.D. et al 2001) investigated the effect of communication skills training for nursing assistants on their verbal interactions with nursing home residents during care routines. The residents had moderate cognitive impairment with intact communication abilities. In the intervention group 52.94% had dementia and in the comparison group 72.73% had dementia. The nursing assistants were taught to use communication skills and memory books when interacting with the residents. A staff motivation system was utilised to encourage the nursing assistants to use the skills. A comparison group received no intervention. The nursing assistants who received the training talked more, used positive statements more frequently and tended to increase the number of specific instructions that they gave to residents. Two months after the research staff left the nursing homes the nursing assistants were maintaining the behaviour. The changes in behaviour did not result in an increase in the time spent providing care to residents. Although changes in nursing assistants’ behaviour were found the rate of resident’s verbal interactions did not increase.

A recent good systematic review (Eggenberger, E. et al 2012) synthesised the evidence on the effectiveness of communications skills training of caregivers in nursing homes and home-care settings. Seven of the included studies were RCT’s, 2 controlled clinical trials and 3 before and after studies. Two of the studies included in this review are also discussed in this synthesis: Burgio, et al 2001, Done and Thomas, 2001. This review found that this type of training can improve the quality of life and wellbeing of people with dementia in both nursing home and home-care settings. Additionally, the training can increase positive communication in nursing home and home settings. The training impacted significantly on the professional and family caregivers’ knowledge, competencies and communication skills. However, the review found inconsistent results around challenging behaviour, the use of restraints and the use of sedative drugs. Also, problems with the randomisation process and the blinding of study personnel were found in the majority of the RCT’s. The review believed that the methodological quality of RCT’s was felt to be improving but further studies using robust methodology and validated communication outcome measures are required.

A controlled clinical trial (Ripich, D. N. et al 1998) investigated the impact of a training program on the communication interactions of caregivers of persons with early to mid-stage Alzheimer’s disease after one year. The communication programmes was FOCUSED a programme developed for carers of patients with Alzheimer’s disease and used in earlier studies. Compared to the comparison group the caregivers that received the training had higher scores for knowledge of Alzheimer’s disease and communication. The FOCUSED communication group had a reduced number of breakdowns in communication from the start of the study to six months but an increased number of hassles from 6 to 12 months. This increase could have due to patient’s normal disease deterioration. This small study showed that the FOCUSED communication training programme improved caregivers’ knowledge of Alzheimer’s disease and communication and initially decreased the number of communication hassles.

Another controlled clinical trial conducted in America (Ripich, D. N. et al 1999) also investigated the impact of the FOCUSED communication programme on caregivers of individuals with Alzheimer’s disease. Caregivers were assigned to the FOCUSED programme, the FOCUSED booster
programme or a comparison group. Participants in the FOCUSED and FOCUSED booster group received communication training from a speech language pathologist in groups. Participants in the booster group also received training tapes and follow-up phone calls. Six months after the intervention caregivers in both FOCUSED groups asked fewer open-ended questions than caregivers in the comparison group. From 6 to 12 months though the two FOCUSED groups increased the number of open-ended questions they asked. Decreasing question success over time was expected for all groups as the cognitive status of Alzheimer’s disease patients declined over the year. The study results suggest that caregivers can be trained to structure questions to enable more successful communication interaction with people with Alzheimer’s disease.

A clinical trial in the UK (Done, D. J. and Thomas, J. A. 2001) evaluated whether a short training workshop on communication techniques was more effective than an information booklet for improving the communication skills of informal carers of people suffering from dementia. Carers attended a workshop or received a booklet. The workshop group attended a communication training workshop led by a speech language therapist. The booklet group were given the booklet and informed that it contained useful advice that they would find relevant. Carers’ awareness of communication strategies was initially low and improved at follow-up for both groups. The workshop group’s knowledge increased significantly more that the booklet groups. The carers stress levels did not change after the intervention. At follow-up there was a significant reduction in reports of problem communication in both groups; reports of problem behaviour remained the same. Qualitative analysis of the carers’ feedback found that benefits were more frequently reported in the workshop group and that the package was only likely to be found valuable in the early stages of dementia.

Another small innovative clinical trial (Murphy and Oliver, 2013) conducted in Scotland and the north of England investigated using Talking Mats framework to help people with dementia and their carers discuss issues around daily living and make joint decisions. The Talking Mats are a low technology, simple, accessible and inexpensive Augmentative and Alternative Communication system that can be easily used in any setting. Eighteen couples were observed discussing four topics using the Talking Mats and their usual communication methods. Additionally, participants individually completed a short questionnaire to determine how involved they felt in the discussion. The study found that both the person with dementia and the carer felt more involved in discussions when using the Talking Mats framework and more satisfied with the outcome of discussions that when using their usual communication methods. The findings of this small study are promising but the small study sample mean that caution must be taken in generalising the findings to the wider population of people with dementia and their carers. A key strength of this small study though was the combination of quantitative and qualitative data with qualitative data providing useful additional information.

A clinical trial (Dijksra, K. et al 2002), investigating a subset of an RCT, assessed the impact of a communication intervention on the interactions between nursing home residents and the nursing assistants assigned to care for them. The residents all had dementia, early, middle or late stage, and had retained at least some expressive and receptive language. Nursing assistants attended a 1-hour in-service training session on communication skills and using memory books and then 2-4 weeks of hands-on training during care routines or were in a comparison group. The study results indicated benefits of the intervention programme with regard to most discourse characteristics. Residents in the late-stage of dementia received the greatest benefits from the intervention. The
finding from this study suggests that further studies in this area should focus on residents with middle and late-stage dementia for the best results.

Another controlled clinical trial (Broughton, M. et al 2011) conducted in Australia evaluated a DVD-based training programme entitled RECAPS and MESSAGE for nursing home staff. The programme is designed to provide caregivers, working with residents with dementia, with strategies to support their memory and communication. Knowledge of memory and support strategies and caregiver satisfaction were measured at baseline, straight after the training and 3 months after the training for the control and training group. Caregiver’s knowledge increased in the training group from baseline to post-training. This improvement was significant in the training but not the control group. Caregiver satisfaction only improved at 3 months for qualified nurses though. The training programme increased knowledge and was acceptable to staff and thought to be useful. The RECAPS and MESSAGE training programme was also investigated in another clinical trial (Liddle, J. et al 2012) in Australia. The second study investigated the effectiveness of the intervention on informal caregivers in community setting. Outcome measures were carer’s knowledge of memory and communication strategies and their perceptions of problem behaviours. Participants with dementia was also assessed for depression and well-being. The training programme was found to increase the knowledge of the caregivers and the training group also reported a decrease in frequency of problem behaviours. Patients with dementia with caregivers in the training group had more depressive behaviours. The DVD programme again demonstrated positive results for knowledge of caregivers. Further research into the DVD programme with a larger sample would be beneficial and could investigate further the increase in depressive behaviour.

An RCT conducted in France (de Rotrou, J. et al 2011) investigated a psycho-educational programme for family caregivers. Participants were family caregivers of family members with mild to moderate Alzheimer’s Disease being treated with drugs. The intervention group received 12 group sessions lasting for 2 hours each over 3 months while the control group received usual care. Outcomes assessed in the study were functional status of patients with Alzheimer’s disease. Caregivers were assessed for depression and their sense of competence. Assessments were at baseline, 3 months and 6 months. Patients’ functional status stabilised in the intervention and control group. Caregiver’s in the intervention group had significantly better understanding of dementia at 3 and 6 months and a better ability to cope at 6 months. The programme helped carers to understand the disease better and improved their sense of coping but there were no improvements for the patients themselves.

Another RCT (Kouri, K.K. et al 2011) investigated a psycho-education intervention focused on communication for caregivers with a family member with early-stage dementing disease in Canada. The study considered the effects of the intervention on caregiver knowledge, perceptions of difficulties in communication, degree of problems related to communication difficulties, self-efficacy and skills. The intervention was delivered over a period of five weeks with weekly personalised sessions lasting 90 to 120 minutes. The study found that there were significant effects on caregiver knowledge, self-efficacy, skills and degree of disturbance related to communication difficulties when caregivers in the intervention group were compared with a control group who received a leaflet on communication and memory. At the follow-up, 6 weeks after the intervention, delayed effects were found in communication skills. Findings from this study suggest that the communication programme could be beneficial in helping caregivers adjust to their new role. However, the study sample was
small comprising 50 caregivers and the assessment of communication knowledge and skills used 2 new measures.

Another clinical trial (Haberstroh, et al 2011) conducted in Germany investigated a communication training programme for the informal carers of people with dementia based on the TANDEM model. The 5 training sessions were led by a professional trainer but utilised the experience of the caregivers and a key part of the training was the encouraging the caregivers to discuss their experiences together. The study found that following the TANDEM intervention caregivers increased their use of strategies designed to improve communication with people with dementia. The quality of life of the person been cared for improved. The small study sample means that caution must be used if generalising to the wider population. Additionally, the study was unable to randomly assign participants to the intervention and control group.

The findings from these studies suggest that educating caregivers (both paid and family members) about dementia, communication strategies and training in communication skills can help them to improve their understanding of the disease and their interactions with the individual or individuals they are caring for.

**Treatment of anomia**

Anomia or a problem with word finding is a common difficulty for people with dementia, four of the studies investigated treatments for anomia.

A literature review (Henry, M.L. et al 2008) considered the available literature on the nature and treatment of anomia in individuals with semantic dementia. The review found limited research into treatments for anomia and the authors conclude that treatment may only be realistic during the early stages of semantic dementia. Additionally, three studies discussed previously (Ousset, P.J. et al 2012 Reilly, J. et al 2005 and Noonan, K.A. et al 2012) investigated treatments for anomia.

**Management of dysphagia in dementia**

Four of the studies considered the management of dysphagia in patients with dementia. There were two systematic reviews and two surveys.

One good systematic review (Alagiakrishnan, K, et al 2013) investigated the evaluation and management of oropharyngeal dysphagia in dementia. The review synthesised international research from 1990 to 2011. Dysphagia may develop during the early stage of Alzheimer’s dementia but commonly develops during the late stages of frontotemporal dementia. There was limited evidence for the usefulness of diagnostic tests and the effect of management strategies. The review highlights the significant gaps in the evidence on the evaluation and management of dementia patients with dysphagia.

The other systematic review and the two surveys focused specifically on the use of tube feeding in patients with advanced dementia. Tube feeding is introduced for patients having trouble swallowing or with poor nutritional intake. An excellent systematic review (Candy, B. et al 2009) synthesised the evidence on enteral tube feeding in older people suffering from advanced dementia. The review included seven controlled observational studies, no RCTs, controlled clinical trials or controlled
before and after studies or time-series studies were retrieved in the literature search. Six of the included studies investigated mortality and the other focussed on nutritional outcomes. The effect on a patient’s quality of life was not investigated. The review found insufficient evidence for benefits of tube feeding for patients with advanced dementia. Importantly, data on the adverse effects of tube feeding in this patient group is unavailable. Whereas papers have reflected on the complex ethical issues associated with this intervention with persons with dementia (Norberg, A. t al 1980 and Gillick, M. 2000).

The two surveys surveyed speech-language pathologists in America (Sharp, H. M. and Shega, J.W. 2009 and Vitale, C.A. et al 2011). The earlier surveys asked 1050 speech-language pathologists about their beliefs and practices on the use of percutaneous endoscopic gastrostomy (PEG) tube feeding in patients with advanced dementia and dysphagia. 57% of the sample responded to the survey giving 326 surveys for analysis. Of the included surveys 56% would recommend PEG for this patient group. Evidence on the benefits of PEG feeding in this group is insufficient but many of the respondents believed that it increased survival and improved nutritional status in this patient group. The findings from this study demonstrate that it is important that speech-language pathologists keep up-to-date with evidence for their practice and that measures to facilitate this might need to be implemented. The later survey considers the same patient group and investigated US speech-language pathologists' knowledge and practice related to tube feeding. Of the 1500 speech-language pathologists sampled 731 returned usable surveys. 42.1 of respondents believed that they could manage dysphagia appropriately, only 22.0% were aware that tube feeding was unlikely to prevent an uncomfortable death or enhance a patient’s quality of life. A larger majority (70%) would recommend oral feeding despite high risks of aspiration. Speech-language pathologists with more experience had better knowledge about tube feeding.

Interventions delivered by

The interventions in the included studies were delivered by Speech and Language Therapist or Pathologists, patient’s main caregiver nursing home staff or family members, and students.

Speech Language Therapists

Six of the interventions discussed above were administered by Speech Language therapists or their American equivalent Speech Language Pathologists (Zientz, J. et al 2007a, Ripich, D. N. at al 1998, Ripich, D. N. at al 1999, Done, D.J. and Thomas, J.A. 2001 Santo Pietro, 1998 and Senaha, M. et al 2010 ). The studies together indicate that Speech Language Therapists can deliver interventions directly to patients with dementing disease or to their carers that improve their communication interactions and functioning.

Students

Two of the interventions discussed in the synthesis were delivered by students (Mahendra, N. and Arkin, S. 2003 and Arkin, S. 2007 and Arkin and Mahendra, 2001. These studies suggest that students can usefully be involved in delivering interventions to patients with dementia.
Caregivers administered interventions

Two systematic reviews reviewed the evidence on interventions administered by caregivers (Zientz, J. 2007b and Brodaty, H. and Arasaratnam, C. 2012). The earlier review included three studies which aimed to maintain over time levels of cognitive and behavioural functioning in individuals with Alzheimer’s disease. The studies reviewed found that family caregivers can be trained to administer intervention programmes to their partner of family member with Alzheimer’s disease at home. Results from the studies were generally positive and demonstrated benefits for both individuals with mild to moderate Alzheimer’s disease and their family caregivers. The later review including meta-analysis investigated the effectiveness of nonpharmacological interventions delivered by family caregivers in a community setting on the management of behavioural and psychological symptoms of dementia. Interventions were found to be effective in reducing behavioural and psychological symptoms associated with dementia. However, the sample sizes investigated and the methodological quality of the studies varied weakening the strength of any recommendations.

Summary

The intervention studies reviewed in this synthesis demonstrate that interventions can help to slow the decline in cognitive functioning, help maintain vocabulary and improve the communication of patients with dementia. Multi-modality intervention that included physical exercise, volunteer work and exercises to help memory and language can have beneficial effects providing participants are physically able to complete the intervention. Additionally, the breakfast club was another successful multi-modality programme. The training of caregivers of patients with dementia about the disease, communication strategies and the use of memory books and wallets can help to improve their communication interactions with patients. Interventions were successfully administered by speech language therapist, students and carers. To ensure that interventions are successful it is important to tailor them to the individual patient and their diagnosis.
References


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