

Non-pharmacological therapies for people with dementia; key facts

When treatments for persons with Alzheimer's and other forms of dementia are being considered, it is usually medication that is the focus. The development of new drugs and their availability has received considerable attention, from the media, the public, professionals and family care-givers as well as from persons with dementia. Recently, the question of the value of other forms of treatment for persons with dementia has been scientifically addressed, and the evidence for their effects begun to be systematically studied.

This position statement aims to set out what is already known regarding other forms of treatment and to emphasise the need for further development work and research in this area. These treatments which do not involve the use of drugs (but may be used in conjunction with pharmacological treatment) can be broadly defined as 'non-pharmacological therapies' (or NPTs). They are wide ranging in approach and encompass psychological, psychosocial, interpersonal, behavioural, emotional, exercise and environmental interventions. They reflect a variety of approaches, and the creativity and commitment of many professional and lay carers of persons with dementia around the world. They include approaches as diverse as cognitive training, the therapeutic use of music, physical exercise, massage, reminiscence therapy, education for care-givers, support groups and psychotherapy.

It is widely accepted that the care environment (physical and social) and day-to-day interactions between care-givers and persons with dementia can have a considerable impact. This means that virtually all dementia care has the potential to be therapeutic. NPTs are typically structured approaches, targeted at particular goals or outcomes; they should enable the identification and sharing of effective care practices and build on and add to the effects of good quality day-to-day care.

What are the goals of non-pharmacological therapies?

It is important to emphasise that NPTs are not seen as providing a cure for dementia. They aim to make a difference in some or all of the following ways:

- Through **improving the person's cognition**, in areas such as memory, concentration, language skills or reasoning. Typically changes in these areas would not be seen as sufficient in their own right to justify the use of an NPT, unless there is an effect on the person's performance in real-life situations or an associated improvement in the person's well-being, self esteem, mood and behaviour.
- Through **improving the person's ability to function** in real-life, everyday situations, helping to maintain the person's independence for as long as possible; these goals may range, for example, from remembering appointments or food preparation in mild dementia, to improving dressing skills in instances where the dementia is more severe.
- Through the **reduction of distress and mood disturbances** in the person with dementia, for example, by reducing depression and anxiety or by increasing adjustment or coping in the early-stages of dementia.
- Through enhancing the person's **quality of life**.
- Through **positive changes in the care-giver**; these can include reduced depression, distress or anxiety; reduced burden; increased coping skills; less distress regarding difficult behaviours; improved understanding and support from family and friends, and enhanced quality of life.

- Through **changes in disturbing and distressing behaviours**, such as aggression, inappropriate sexual behaviour, restlessness. Depending on the behaviour and the factors contributing to it, the goal may be to reduce the frequency of the behaviour, or its severity; where the behaviour does not appear to be causing problems for the person with dementia, the goal may be to reduce the impact of the behaviour on others, including family care-givers or care-workers.

Some goals for persons with dementia may be short-term or immediate; for example, a hand massage or a music session may aim to calm the person with dementia for the duration of the session, without necessarily having any noticeable effect one hour later. For someone who is rarely calm, this may be a valuable achievement; if there is an approach that has more lasting effects, however, that might be preferred. Just as pain-killers may only have an effect for a limited time but are still valued, so there may be instances where the achievement of short-term goals – in terms of enjoyment, pleasure or relief from distress and suffering – is worthwhile.

The likelihood of further decline in dementia means that even where improvements do continue after the intervention session, it is usually necessary to plan further input, perhaps in the form of booster sessions, to maintain improvements.

Is there any evidence that non-pharmacological interventions are effective?

The evidence from research studies on NPTs has been reviewed by groups in several countries, and by international collaborative groups, including the International Non-Pharmacological Therapies Project. There is general agreement that the research on NPTs has been varied both in quality and outcomes. Partly due to lack of funding for research on NPTs, high quality studies are scarce and that there is almost a complete absence of evidence on the effectiveness of some well-established approaches.

However, there are promising indications of the effectiveness of certain interventions. These include:

- Certain **interventions with family care-givers**, involving an individualised package, combining several approaches based on a comprehensive assessment of the caregiver, the patient, the family and the social environment. Components of this intervention may include training and education, use of resources (day care, support groups, respite services, etc.), organizing additional family support, etc. There is strong evidence that this inexpensive, flexible intervention improves psychological well-being of the caregiver, and prevents or delays costly care home placement.
- A combination of therapies for the **person with dementia**, including cognitive stimulation, physical exercise and other components in different proportions has been demonstrated to improve daily functioning, cognitive capacity and mood (reducing depression), whilst also reducing behavioural symptoms that can severely distress caregivers.
- Behavioural interventions to reduce **disturbed behaviour**, involving individual work with family care-givers or training for care-workers have been shown to be effective in a number of studies.

These approaches have all been evaluated in randomised controlled trials, with the effects assessed by raters not involved in the delivery of the therapy. They are listed to indicate the range of approaches which already have evidence established for their effectiveness.

Inevitably, there is more evidence available on approaches which can be packaged and delivered in a standard and consistent manner. Approaches aiming to change the care environment, through design changes or through staff training, are more difficult to evaluate rigorously. Approaches requiring a great deal of individualisation of the treatment approach, e.g. behavioural analysis of challenging behaviour, have similarly tended to be evaluated less often. However, researchers are now giving more attention to evaluating individually tailored approaches, which can be delivered within a consistent framework of assessment and intervention.

Do non-pharmacological interventions have any harmful side-effects?

One of the benefits of NPTs is the relative lack of negative effects, compared with many medications, such as those used for challenging behaviour. However, caution must be used with any intervention to avoid delivery in a manner which devalues, dehumanises or patronises the person with dementia. The underlying principles and values of person-centred care are embodied in the following statement:

‘A person with dementia is a person of worth and dignity, deserving the same respect as any other human being’ (ADI Charter of Principles, 2003).

All NPTs require this attitude of respect for the person as an essential basis for their implementation. Difficulties arise where the choices and preferences of persons with dementia are not given proper respect and consideration, or where inappropriate goals for intervention are selected. For example, a person with early-stage dementia whose preferred way of coping is to minimise his or her memory problems may be unwilling to engage in an intervention such as a memory re-training group. Recognising that no one approach will suit everyone is essential if the value of NPTs is to be realised. One person may find a hand massage relaxing, another may find it an intrusion; one person may enjoy a particular piece of music, another may find it irritating and unpleasant. Negative effects will occur where there is an attempt to apply an approach without considering individual differences, preferences, reactions and remaining abilities.

Balancing costs and benefits

A possible negative effect may sometimes occur where the potential benefits of an NPT are over-stated, and the family care-giver and person with dementia experience disappointment when the promised changes do not materialise. In considering any NPT, it is also important to consider the balance of costs and benefits. If the costs are low, then it might be worth pursuing, even if the likelihood of benefits is relatively low; on the other hand, a high cost approach would require a higher probability of goals being achieved or a large potential benefit. The costs to be considered include time and effort, as well as financial matters. The balance of outcomes for the person with dementia and family care-giver also needs to be considered. An approach might not be worthwhile if, despite improving function in the person with dementia, the care-giver became more depressed. For example, some studies (of NPTs targeted at family care-givers) have evaluated whether the intervention results in the person with dementia remaining longer at home; this outcome, in a fairly crude way, reflects enhanced quality of life for many people with dementia; however, this needs to be viewed alongside changes in the care-giver’s mood and distress, to be sure that delays in institutionalisation have not been gained with undue negative consequences to the care-giver’s mental or physical health, financial status or quality of life. (In fact, the reverse has typically been the case with reductions in care-giver depression achieved alongside delayed admission to nursing home care.)

Who can implement non-pharmacological approaches?

Some NPTs do require specialist training e.g. cognitive-behaviour therapy for depression in care-givers. However, in most cases, whilst training and supervision from a specialist may be required to initiate these approaches, care-workers without formal qualifications who receive specific training are able to implement the approach as part of a day to day routine.

- Training packs and manuals are available for a number of approaches. The prerequisite is that all those involved in implementation have good person-centred care skills.
- Where the approach involves work in a group, it is good practice to have at least two workers involved in leading the group, with sufficient time allocated for de-briefing.
- Regular supervision sessions from a trained and competent person will be essential to ensure the quality of implementation.
- There is good evidence that family care-givers, with training and support, are able to carry out many NPTs with their relative with dementia; involvement in this way can have positive effects for the care-giver also.

Implementation – what works for whom?

Each person with dementia is unique; there are many different forms and types of dementia, and a wide range of severity, combined with an infinite variety of combinations of life experiences, personality styles, physical health profiles, social networks and care environments. Whilst NPTs are being identified that are effective for the ‘average person’ with dementia of a certain level of severity, more information is still needed about how to select an approach that will be best suited to each individual.

In practice, the first step is to identify, with the person and his/her supporters, what would be the important areas to focus on – those where a small change could bring about a significant improvement in quality of life. These individual goals can then guide the choice of NPT, bearing in mind the individual pattern and profile of wishes, past and present likes and dislikes, abilities and impairments. What is being developed is a tool-kit of approaches, each of which has its own uses, and its own limitations, so that the interventions used for each person with dementia and their supporters can be individualised. Although each person with dementia is unique, there are marked commonalities, which are dependent on the particular dementia diagnostic type and the stage of dementia

Each NPT needs to be considered in relation to the culture in which it is to be applied; while a medication may have the same impact across different cultures, NPTs are embedded within the cultural context in which they were developed and evaluated, and adaptation and revalidation may be required to make them useful in other environments. Apart from cross-cultural differences in activities and values, the culture of care is also highly relevant: NPTs applied in a rich care environment may have much less impact than when the same approaches are applied in an environment where there has previously been little stimulation or therapeutic input. The intervention plan may, of course, include NPTs in combination with medication; several studies have already suggested there may be added value in this approach in some circumstances.

Future directions

It is clear that **more research is needed** to delineate the effectiveness of the numerous approaches that have yet to be rigorously evaluated, and to provide further guidance on which approaches might be used in particular instances.

- More attention needs to be now given to the development and evaluation of **individually-tailored approaches**, as well as approaches which seek to have benefits

at the level of the **whole care environment**, rather than only at the level of the individual.

- It is important that opportunities remain for the development of **creative, innovative approaches**, but that this is backed up with readiness to carry out careful evaluations of effectiveness, using relevant and appropriate outcome measures. **Alzheimer organisations** have a key role in encouraging both innovative practice and the development of research into NPTs.
- **Resources** for the implementation of NPTs with proven effectiveness and for high-quality research for development and testing of NPTs needs to be made available alongside resources for medication and for biomedical research, as a proper response to the wide-ranging impact of the dementias.

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Further reading / useful web-sites

Alzheimer's Disease International Charter of principles for the care of people with dementia and their carers: <http://www.alz.co.uk/adi/charter.html>

Web-site for the International Non-Pharmacological Therapies Project:
www.NPTherapies.org

Web-site on cognitive stimulation for people with dementia: www.cstdementia.com

NICE-SCIE Guideline on the management of dementia:
<http://egap.evidence.nhs.uk/CG42/guidance/>