

Contented Dementia Trust

Sustainable quality of life



The **SPECIAL**[®] *Method*

Contented Dementia Trust

The Contented Dementia Trust (formerly known as SPECAL) promotes lifelong well-being for people with dementia.

Our vision is as profound as it is simple: a world where the onset of dementia is no longer viewed with fear because it is possible to sustain well-being all day, every day, for life, even with a diagnosis of dementia.

Constant media coverage of the escalating numbers of people affected by dementia and the impact of the condition on individual lives fuels fear and anxiety. Many of those affected or involved feel that there is little that can be done to help: even if medication can temporarily delay the worst of the symptoms, the only course appears to be to 'hope for the best', but with little idea of how that can be achieved.

"A friend gave me a copy of 'Contented Dementia'. It was the first time I'd seen the words 'dementia' and 'positive approach' together, so I booked myself on a training course. The SPECAL method has literally transformed my mother's life – and mine. I would encourage anyone who cares for a person with dementia to explore SPECAL - it works!"

The original name of our charity - SPECAL - began as an acronym for Specialized Early Care for Alzheimer's. The word 'SPECAL' is now used to describe a unique dementia management method that can be learned and used by anyone involved in the care of a person with dementia. Use of the SPECAL method can bring about immediate and sustainable improvements in the quality of life of the person with dementia and for everyone involved in their care.

The SPECAL method is tailor-made for the condition of dementia, whatever the cause. At the Contented Dementia Trust we see the condition as a disability and work positively with it, rather than trying to ignore or defeat it. Our model really works - when the SPECAL method is applied, the condition becomes a disability that can be managed with remarkable success. The SPECAL method can slow the rate of deterioration and enable people to function without drugs, to remain in their own homes for significantly longer, and to avoid the distress all too often seen during the transition into another care setting.

The SPECAL method is based on an innovative way of understanding dementia from the point of view of the person with the condition. We explain this using a simple analogy - the SPECAL Photograph Album - which everyone coming into contact with the person with dementia needs to understand.

Our aim is to spread this positive message and share the SPECAL Photograph Album and its associated method with everyone whose life has been touched by dementia in any way.

“You have made such a difference to how I am able to be about mum’s dementia”.

The key to understanding the SPECAL method is the SPECAL Photograph Album.



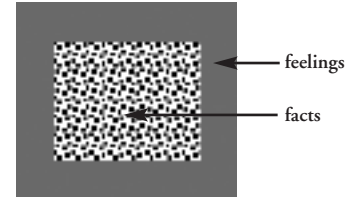
“I had such a happy time with my father because I had an understanding of what it is like to have dementia. It was inspiring to know that he wouldn’t end his life in a miserable sedated state.”

We use the analogy of a photograph album to describe, in a very simple way:

- how normal memory works
- the impact of ageing
- the single dramatic change that occurs with the onset of dementia

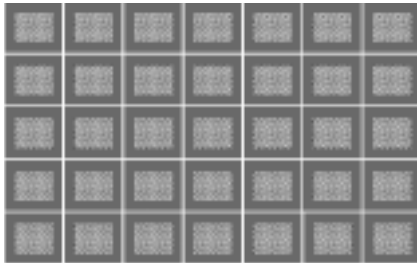
Within the analogy, the ‘photograph album’ represents our memory storehouse, with individual memories represented as ‘photographs’.

Each of our experiences in life is recorded as a photograph and stored in our album. Each photograph has two features: facts and associated feelings.



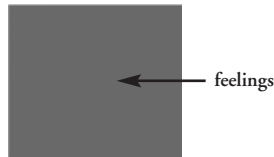
Photographs are stored in our album a split second after each experience, and this storage requires no effort from us whatsoever. The taking and storing of photographs is a continuous, automatic and unconscious process going on in the background of our life, unobserved by us and unobservable by anyone else at the time of storage. Our album falls open quite naturally at today’s page, where the latest photographs are arriving, so that we can constantly check what has just happened in our life a few moments ago. This provides us with the context we need all the time for what we are doing, who with, where, when and why.

Every time we say ‘Now, let me think...’ we mean ‘Let me look in my album’.

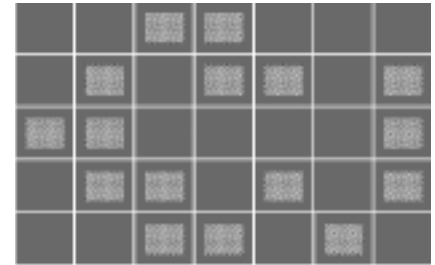
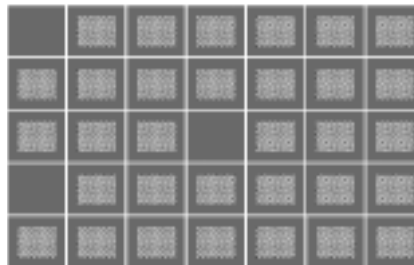


As we age, there is no change in the way in which photographs are taken and stored, but we become progressively slower at finding the photographs we need. The photographs are there, but sometimes we are so slow in finding them that the moment has passed. Of course, as eyesight and hearing diminish with age, we may have less detail in our album than others expect us to have: we only store what we have actually experienced.

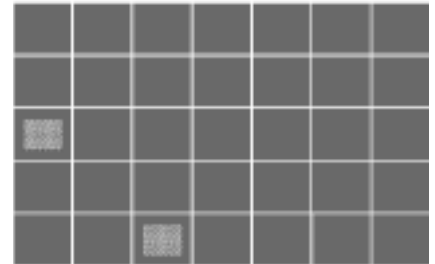
Dementia introduces an entirely new type of photograph: a photograph in which the facts of what has just occurred are not stored, although the feelings associated with the missing facts are stored. We call this new type of fact-free, feelings-only photograph a ‘blank’.



At first there are very few blanks, but they increase in frequency and gradually form long ribbons of blanks, dramatically altering the appearance of today's page in the person's album.

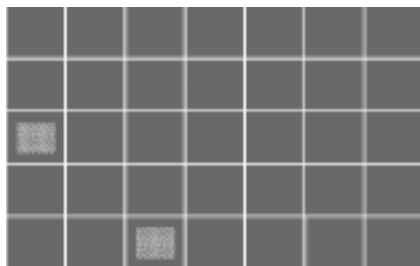
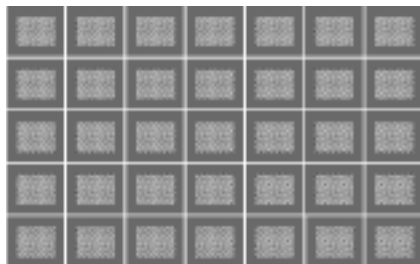


Eventually, feelings become very much more important than facts for the person with dementia.



As the person possesses ever fewer facts about what has just occurred in their life, they will have difficulty making immediate sense of their surroundings.

They will turn back to much older pages in their album, trying to make the most useful match they can between what is happening to them in the present - in the here and now - and other photographs from long ago, before dementia started to disrupt their life.



The SPECAL Photograph Album analogy enables us to understand the impact of dementia, and provides those without dementia with a useful insight into the predicament faced by a person with dementia. The SPECAL Photograph Album understanding of dementia is critical to anyone wanting to deliver effective care to a person with dementia, whether in the family home, in hospital, or in a residential care setting.

An understanding of the SPECAL Photograph Album is fundamental to every element of the SPECAL method. Our training sessions powerfully demonstrate what it must be like to experience dementia; this can be a devastating and humbling insight for those of us without dementia, but it provides the key to managing and minimising the impact of the disease.

“It was like a light bulb coming on. I suddenly realised just what my mother was grappling with. Now at least I understand, and can start helping her rather than trip her up.”

What is different about the SPECAL method?

The SPECAL method introduces a very important change of perspective for the carer, and offers them a completely different way of looking at the condition of dementia. Common sense has to go out of the window when it comes to managing dementia, because it is likely to result in a progressively declining sense of confidence for the person with dementia.

Common sense simply does not work with this condition, and carers need something quite different.

At the Contented Dementia Trust we call this ‘SPECAL sense’ - something that flows from engaging with the experience of dementia as demonstrated by the SPECAL Photograph Album. SPECAL sense enables the carer to take the general experience of dementia fully into account and then go forward with confidence to individualise the way they interact with their particular person.

SPECAL sense is needed by everyone coming into contact with the person with dementia: it enables them to ensure that the person with dementia can lead a life that is as close as possible to the sort of life they would have lived if they had not developed the condition.

“SPECAL sense has meant that I have been able to bring joy and sustainable contentment into his life when no one else could. That’s something I’ll never forget.”

What is meant by SPECAL sense?

SPECAL sense is counter-intuitive, and begins with Three Golden Rules:

1. “Don’t ask questions”

Avoid asking any direct question that requires the person with dementia to search their photograph album for factual information that may not have been stored. Their desperate search for missing facts will only increase their perception of their own disability, causing them unnecessary distress. It is surprising how much information you can gather from the person with dementia without asking direct questions.

“Just stopping asking questions has completely altered our life. I cannot believe the change. Her distress has evaporated. We have got her back again.”

2. “Listen to the expert (the person with dementia) and learn from them”

Listen to the questions the person with dementia is asking, and consider very carefully what the best answer might be for them. SPECAL training starts with looking at the most frequently asked questions. For people with dementia, feelings are more important than facts, and the information that is given to them from now on must generate good feelings for them. There is a moral imperative not to cause them any more anxiety than they are already experiencing. Once you have found the best answer to a question, it should be used consistently by everyone coming into contact with the person. Then move on to the next most frequent question. Carers using the SPECAL method find that the anxious questioning gradually subsides.

“My mother kept asking where the dog was. I tried over and over again to explain that the dog had died. Then I went on a SPECAL course and decided to try saying that the dog was fast asleep. She sighed with relief. It was just a different answer, that’s all, but it made such a difference.”

3. “Don’t contradict”

Do not argue with the person with dementia. They are increasingly likely to seek out old photographs from their pre-dementia past, in order to understand what is happening in the present. We need to take careful note of the person’s language when they do this, so that we can adapt to them, rather than expecting them to follow our lead.

“Nowadays I try and say something like ‘I expect you’re right’, and straight away the problem that was brewing just seems to vanish.”

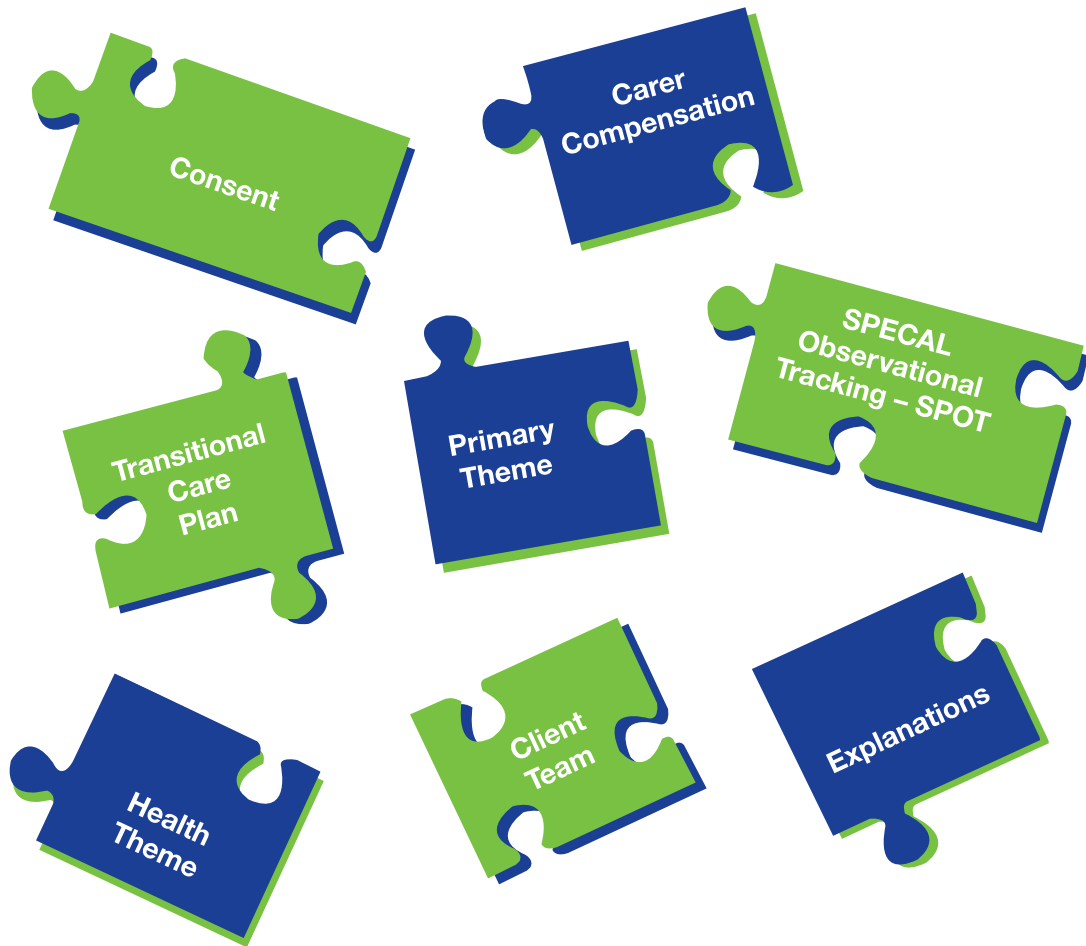
The Three Golden Rules may seem counter-intuitive, but once implemented by everyone coming into contact with the person with dementia, the benefits quickly become self-evident and life will be much easier. Once SPECAL sense is used, many other aspects of caring for the person with dementia will begin to fall into place.

The Three Golden Rules apply to each and every person with dementia, and will make a remarkable difference as soon as they are introduced, but they are not enough to sustain well-being for life. Each person’s life history is different, and individual profiling is essential if we are to get to a point where we can sustain well-being until the end of the person’s life.

Once these general Golden Rules have been taken on board, the next step in the SPECAL method is to build a personalised SPECAL Care Profile that contains the carefully collected and organised biographical details and background information about the individual with dementia.

How do you build a SPECAL Care Profile?

The process of creating a SPECAL Care Profile is like assembling a jigsaw of different pieces which fit together to form the completed puzzle. The jigsaw pieces provide the components needed for 24 hour individualised care for the person with dementia.



Consent

Carer
Compensation

Transitional
Care
Plan

Primary
Theme

SPECIAL
Observational
Tracking - SPOT

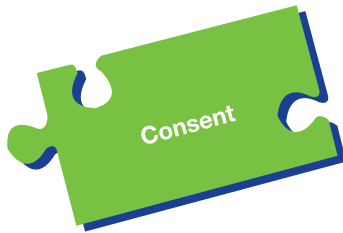
Health
Theme

Client
Team

Explanations

As the dementia progresses, so the care as defined by the jigsaw can be recycled: the person with dementia will not get bored of a repetition of what they enjoy, precisely because they have dementia.

“It isn’t about any one thing - there are several bits and pieces which all fit together and are just starting to make sense. I’m beginning to see what you mean about a jigsaw puzzle!”



The SPECAL Photograph Album way of understanding dementia enables carers to take careful account of consent. Consent is a two-way process: it must be appropriately given and also appropriately received and acted upon.

The SPECAL method incorporates a specific tool to help carers make quite sure that consent is in place - SPECAL Observational Tracking (SPOT).



SPOT is an essential tool for carers, which:

- ensures that the person with dementia is able to communicate and that others understand what is being communicated
- ensures that the person with dementia is consulted in a way which takes full account of their well-being
- enables the person with dementia to give or withhold their consent for what is happening in their life

- enables the caregiver to adapt their care on a moment by moment basis, depending on the information being conveyed by the person with dementia

“My wife trusts me - she has told me that, and I am not going to let her down. I know what she would want me to do, and what she would do in my place. SPECAL has given me the insight I need to carry out her wishes. I know that I have her consent and this gives me the courage to do the best for her.”



The Primary Theme is drawn from the person’s pre-dementia past, and

represents an area of interest that has previously provided a feeling of self-fulfilment and confidence. SPECAL gathers specialised vocabulary relating to the person's Primary Theme, as this can be used in ways which enable the person with dementia to 'help' others. This is highly significant in terms of restoring their sense of independence and worth.

"We've got the hang of the way to use the Primary Theme, and the results are amazing. Even my brother, who was extremely sceptical, is convinced."

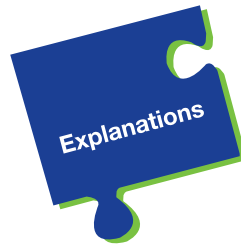


The Health Theme is drawn from the person's pre-dementia past, and

represents an acceptable reason why the person should take care of themselves and allow others to help them to do this. The Health Theme has an important part to play in enabling the person with dementia to accept help without loss of dignity, and provides the counter-balance to the Primary Theme.

"My father has had diabetes for many years. He understands the need to take care of his health."

"Grandma has never been ill and is happy to accept help so that she can stay that way."



The person with dementia needs to be offered explanations that enable them

to make sense of their present without needing to reference what has just been happening moments before.

"Finding the most acceptable answers to my sister's questions has been crucial to her peace of mind."



Everyone coming into contact with a person with dementia needs to understand the SPECAL Photograph Album concept and how to apply the SPECAL method. This ensures that the person with dementia is always in the company of people who understand their disability and are able to compensate for it, minimising anxiety and confusion.

"This is amazing - the first time our family has ever agreed collectively about anything!"

“It’s such a relief to know that everyone understands and feels positive about what we can all do if we work together.”



Every carer - whether family, friend, or professional - has to adapt and change to help the person with dementia. The SPECAL method helps carers to find a sense of achievement in doing so: family members and friends find benefits for themselves through the help they offer.

“I have such joy when I see the look of faith in my mother’s eyes and know that I am giving her confidence. It’s difficult to put into words but it is there.”

“I suddenly realised I was actually looking forward to coming to work. It was a bit of a ‘wow’ moment!”

We encourage the main carer to take up a new project to protect themselves from becoming too dependent on their caring role for their own identity. We build mentoring support into our training for professional carers.

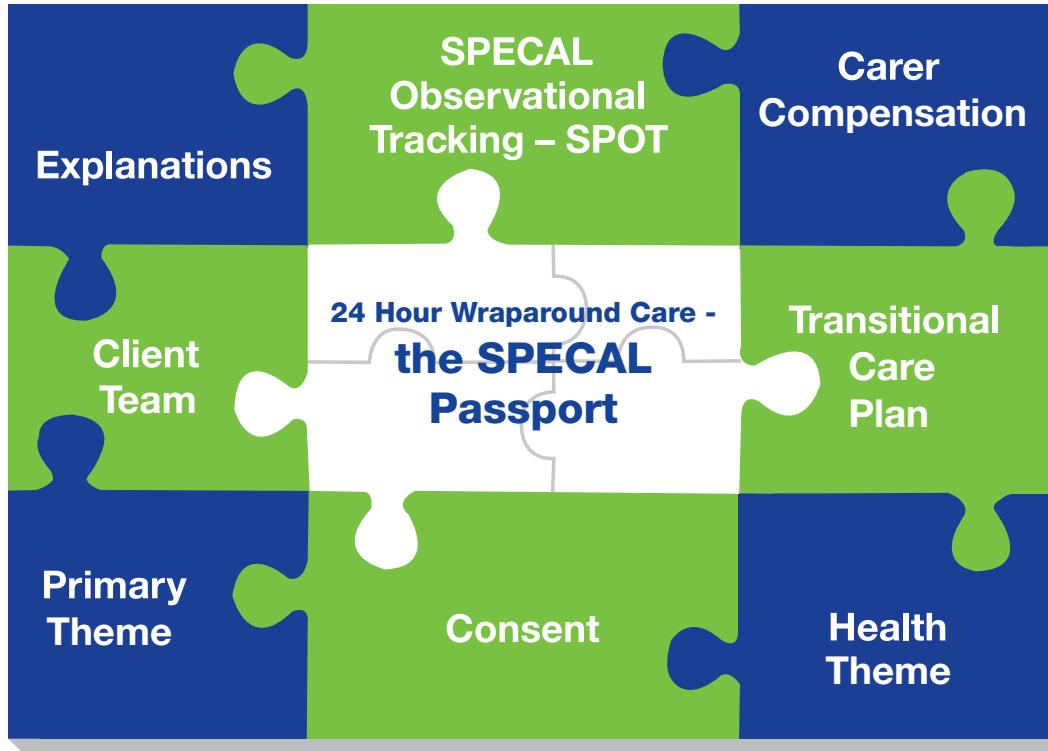
“I am impressed by the way that the carer’s needs are addressed as well as those of the person with dementia.”



The SPECAL method helps families to work together in identifying an appropriate care home setting, should

this be needed in the future. We advise that selection of a care home is best carried out before a crisis occurs in the care of the person with dementia. Early selection of a care home helps the family to feel confident that there is a plan in place, should it be needed. It has been shown that this confidence increases the length of time that the person with dementia is likely to remain in their own family home. The family is able to build up a relationship with the selected care home and to ensure that the staff understand the general principles of the SPECAL Photograph Album and the application of the SPECAL method to the care of their particular person with dementia, ahead of any future move.

“We didn’t want to face up to that one...it was hard...but we’ve been there and chosen one. It’s a huge relief, but I never thought it would be until I took the plunge.”



Each component of the Profile needs to be individualised to the particular person with dementia, leading to 24 Hour Wraparound Care and, ultimately, the production of their SPECAL Passport to lifelong well-being. We call this process 'MAKING A PRESENT OF THE PAST.'[®]

The SPECAL Care Profile provides everything needed by the family wishing to ensure sustained quality of life for everyone following a diagnosis of dementia. Once all the corner pieces and straight edges are fully individualised and securely interlocked, the jigsaw will not fall apart no matter what unexpected events intervene. The central pieces represent the small variations which occur each day. These pieces can be fitted together by the carer in many different ways within the basic framework of the jigsaw to promote a sustainable quality of life for the particular person concerned.

The SPECAL Passport

If, for any reason, a move to a care home becomes necessary, the information contained in the SPECAL Care Profile can be reduced to a single page of A4, known as the SPECAL Passport. The Passport provides the

hospital or nursing home staff with all the key information that they require to provide a continuity of fully individualised, dementia-specific care for that particular person in any 24 hour period.

Where is the Contented Dementia Trust based?

Burford in Oxfordshire has been home to the SPECAL method since 1990. The prevailing wisdom within dementia services in those days was that little or nothing could be learned from or done for a person with dementia. A small team, led by Penny Garner, adopted a very different approach as they began working closely with people with dementia in the daycare and inpatient departments of Burford Hospital. Penny and her team worked together over a ten year period, often around the clock, to observe and record in minute detail what each person with

dementia was saying and doing. Gradually the team developed effective ways of communicating with each individual patient: ways which seemed counter-intuitive to the hospital staff until they saw for themselves just how well the SPECAL method worked.

Working with many hundreds of individuals at very different stages of dementia, the Burford team produced unparalleled results. In 1999 the Royal College of Nursing conducted a formal evaluation of the SPECAL Project* and found the following of patients who had received SPECAL care:

...they experience well-being...they take fewer drugs...they remain at home longer...if it becomes necessary they can move into nursing care with less distress...they demonstrate a plateau effect in the progression of their disease...and are supported by carers who experience less guilt.

Our Centre of Excellence

It is over 21 years since the SPECAL method was introduced at Burford, and the Contented Dementia Trust now owns the Old Hospital site. It has become our Centre of Excellence - a unique environment where we work with family, friends, health and social care professionals and researchers, as we begin to pass on the skills which we have acquired over the years and to demonstrate their effectiveness in a measurable way.

The Friday Group

The first SPECAL care environment was introduced at Burford Hospital in 1990, as part of the multi-disciplinary daycare service, in collaboration with the NHS. This specialised setting was

originally known as the Friday Group and today provides an environment where people at all stages of dementia are able to sustain well-being. It plays a key role in training those who wish to learn the skills necessary to address dementia care and become qualified SPECAL Practitioners.

“I could not believe my own eyes when I came to Burford. I simply couldn’t tell who had dementia and who didn’t. It was an epiphany moment for me.”

Training

All our training starts with a thorough grounding in the SPECAL Photograph Album: this is the point of entry for everyone wanting to know more about the SPECAL method. The SPECAL Photograph Album provides a compelling insight into the experience

of the person with dementia and offers a positive way forward for everyone.

SPECAL courses are designed to meet the differing requirements of two distinct categories of carers:

- those who are concerned with a family member or friend with dementia
- professionals whose work brings them into contact with people who have dementia

Full details of all our Family & Friends and Pro courses are available:

- via our website www.contenteddementiastrust.org
- by contacting training@contenteddementiastrust.org

We also offer bespoke courses in various formats and at different locations.

SPECAL workshops are available to develop specific skills and techniques to cope with a wide range of situations arising throughout the dementia journey: these range from the ‘questionless question’ technique needed for the first Golden Rule, through to the complex task of planning a seamless transition to a care home.

We offer **e-mail support** to readers of ‘Contented Dementia’, and anyone who has attended a SPECAL training course may access the Members’ section of our website with its library and higher level dedicated support service.

A ‘**virtual Burford**’ site is under development for people who are unable to attend our training courses at Burford. See our website www.contenteddementiastrust.org for further details.

SPECAL Practitioner Training Programme

We offer a flexible series of courses designed to meet the needs of professionals involved in dementia care at all levels, based on a combination of theoretical and practical elements and offering the opportunity of experiential learning through closely supervised interaction with people with dementia at Burford. The point of entry for all professional training is the one-day SPECAL Pro course.

Further information is available via our website:

www.contenteddementiastrust.org

or by contacting:

training@contenteddementiastrust.org

“It gave us hope. It’s the only training that has helped us.”

Contact details

- info@contenteddementiastrust.org
for all general information/queries
- training@contenteddementiastrust.org
for all training related information/queries

“I can see now that my husband’s dementia means he cannot change. It is me who has to change. No wonder things have been such a mess.”

“Direct, no-nonsense, straightforward advice and practical help.”

“Mum is happy, we’re happy, the carers are all happy, what more can you ask?”



Photograph by Tim Hetherington

A note from Penny Garner

I have spent a large part of my life studying dementia at very close quarters. My respect and admiration for people with dementia knows no bounds. People with dementia have not lost their reason - far from it - but they are losing, on a daily basis, their ability to store new facts, something that the rest of us take completely for granted.

People with dementia turn, not surprisingly, to old pages of their 'photograph album', seeking out facts that they stored many years ago. They use these to make the best match they can to what is happening around them now. We must make sure that we don't hinder them as they come to terms with their disability. Those of us without dementia have the capacity to ensure

that people with dementia thrive, not merely survive. If, in our ignorance, we press on with our own common sense agenda, taking no account of the sense the person with dementia is making of their own experience, we unwittingly defeat their survival mechanism. The fact that their disability is largely hidden from view is no reason to dismiss it or fail to take account of it. Dementia is like an iceberg, with 6/7ths hidden beneath the surface. The SPECAL Photograph Album provides a clear picture of the subjective experience of those with dementia. Once we understand this we can see clearly what we need to be doing to manage dementia in a more helpful, humane and cost-effective way.

"You have helped us disable the worst impact of the disease - my wife still has dementia but somehow it doesn't matter any more."

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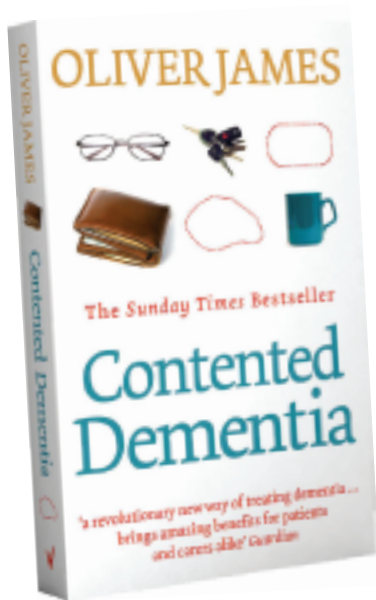
The quotations in this brochure are selected from comments by SPECAL trainees, Friday Group observers and SPECAL-led carers.

* PAGE 12: Pritchard, EJ & Dewing, J (1999). *A multi-method evaluation of a service for people with dementia*. RCN Report No.19. Royal College of Nursing Institute, Oxford.

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“This book really helps explain how dementia affects people and has some fantastic techniques to help those affected to stay happy and secure. If only this were compulsory reading for anyone involved in caring for dementia patients, whether personally or professionally, lives could be transformed.”

“As a consultant and trainer working with clients with dementia, I devoured this book with relish. It’s interesting, practical, well-written and extremely compassionate. In an ideal world this book would be issued as essential reading to all care staff working with older people.”

“It saved us - we were at breaking point with no hope, and it changed our lives forever. I wish everyone knew about it.”

Paperback edition published by Vermilion, can be ordered from our website
www.contenteddementiastrust.org