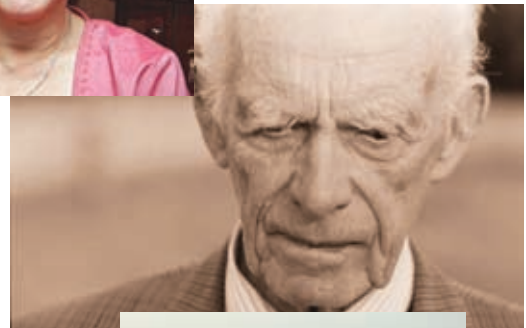


Dysexecutive Syndrome

Dealing with day-to-day decision making

Information for Patients and Carers



Published by Aged Services, Royal Hobart Hospital, Tasmanian Department of Health and Human Services

Contact: Royal Hobart Hospital Aged Services Phone: (03) 6222 7893

The Royal Hobart Hospital Aged Services expects future print runs and we would appreciate helpful suggestions to contribute to future editions.

Email: Ngairi.Pirere@dhhs.tas.gov.au

Copyright

The material contained in this guide is the subject of copyright of the Department of Health and Human Services, Tasmania, all rights reserved. Any material from this guide must not be reproduced in whole or part for commercial sale.

Disclaimer

This guide contains information and suggestions with the object of facilitating understanding of Dysexecutive Syndrome. The information contained within this guide is not a substitute for the advice of an experienced medical practitioner. It is the responsibility of the individual to seek medical advice where clinical need arises. The Department shall have no liability to the users of this guide for any adverse outcomes, loss or damages by the reason of a person relying on the information contained within this guide.

While third party information has been presented with care, the Department does not warrant that the third party information is free from errors or omissions. Any use of the information within this guide is strictly at the reader's own risk. While the clinical information is deemed to be accurate at the time of publishing the Department will not be liable for the accuracy of information that is the subject of change.

Designed and edited by Tina Thornton, Academic Editorial Services (www.academic-edit.com.au)

Printed in Hobart, Tasmania by UniPrint

ISBN 978-0-9599650-5-6

TABLE OF CONTENTS

INTRODUCTION.....	2
CLINICAL OVERVIEW	3
EFFECTS ON BEHAVIOUR	3
Communication	3
Thinking processes	3
How are the person's problem-solving and judgment affected?	4
How are initiative and insight affected?	4
What types of behaviour changes can occur?	4
Self-centred behaviour	5
Irritable and agitated behaviour	5
Compulsive and/or obsessive behaviour	5
Helpful strategies for these behaviours	5
Effects on sleep	6
Helpful communication and memory strategies	6
EFFECTS ON PARTICIPATION IN EVERYDAY ACTIVITIES	8
HYGIENE AND SELF-CARE.....	8
Helpful strategies for self-care behaviours	9
PERSONAL AND OTHER ACTIVITIES OF DAILY LIVING	10
Helpful strategies for activities	10
FEEDING, SWALLOWING AND NUTRITION	11
Helpful strategies for eating, drinking and at mealtimes	11
MOBILITY	12
Helpful strategies to maintain mobility	12
A note on driving	12
FINANCIAL MATTERS	13
WHAT DO CARERS OF A PERSON WITH DYSEXECUTIVE SYNDROME EXPERIENCE?.....	14
Obtaining diagnosis	14
Personality change	14
Disinhibition and embarrassment	14
Role, lifestyle and relationship changes	15
Phases of illness	15
Coping	15
HELP FOR THE FAMILIES, FRIENDS AND CARERS	16
Health care/medication	16
Social networks and supports	16
PLANNING FOR THE FUTURE.....	17
SERVICES IN THE COMMUNITY	17
SUGGESTIONS FOR SUPPORT SERVICES	18

INTRODUCTION

While preparing this booklet the contributors have been mindful of the tragic loss which comes from brain disease and damage, and they believe that it is better to understand the nature and causes. It is important to remember that all the features of Dysexecutive Syndrome described in this booklet may not be apparent, especially early in the course of a disease. The features of the syndrome may range from mild and subtle, to severe and extremely troublesome. The syndrome can be as individual as the person it affects.

Living with or caring for someone with Dysexecutive Syndrome may bring many emotional highs and lows. One carer stated that:

The saddest and most difficult thing is that I no longer have the husband that I married. The shell is still there but that man is gone.

One daughter stated:

My father, my hero, is becoming lost to us all.

Throughout this booklet the written experiences of excellent carers, who generously agreed to participate in the project, are used to demonstrate the nature of the illness. Brief explanatory notes have been added to the carers' statements to provide clarification of which aspect of Dysexecutive Syndrome is being described, or to outline a reason for trying a certain management strategy.

We hope that the information and experiences on these pages will help others make sense of incomprehensible changes in a loved one's words, behaviour, practical ability and personality. For the person with Dysexecutive Syndrome the presence of an understanding and compassionate support network is most important. The role of the health professional is primarily to provide information and moral support, while the ideal of prevention and treatment of brain disorders remains only partially achieved. The limitations of this booklet are freely acknowledged.

I would like to recognise and sincerely thank all those contributors whose enthusiasm and knowledge has made this project possible. They are listed in the appendix at the end of this booklet.

Frank Nicklason

'I can't change the direction of the wind but I can adjust my sails to always reach my destination.' – Jimmy Dean

CLINICAL OVERVIEW

Executive brain function (e.g., insight, judgment, planning and initiative) makes it possible for us to successfully manage the problems of everyday living. We are able to appreciate the situation in which we are living, recognise personal strengths and weaknesses and identify opportunities and threats. Having understood this situation we are able to reflect and evaluate and judge a reasonable course of action, mindful of the possible outcomes of our decision and finally, to review this outcome and make further adjustments/plans as necessary.

Loss of executive function may occur as a result of brain disease or injury; it may arise associated with intellectual disability or psychiatric disorders. It may be permanent (for example as a result of advanced Alzheimer's disease or massive head injury) or transient as a result of delirium due to physical illness or intoxication. Executive dysfunction may be mild and subtle (as only noticed by a close friend or relative) or severe and quite obvious to all. There is a tremendous variability in the manifestations of executive dysfunction with strong influences often apparent from the afflicted person's prior personality, life experiences and intellect.

EFFECTS ON BEHAVIOUR

Communication

Communicating with a person who has Dysexecutive Syndrome can be disconcerting and uncomfortable as they have disruptions in a number of thinking processes that affect behaviour, the use of language and the ability to carry out everyday tasks. Memory, problem-solving, judgment and initiative are essential to daily activities, communication with others and general behaviour.

Thinking processes

How is the person's memory affected?

It is common, at least in the early stages of brain disorders such as Alzheimer's disease, for there to be an awareness (generally troubling) that something is 'wrong'.

Some years after her fiftieth birthday she became increasingly forgetful and often asked 'what is wrong with me?'

I had noticed prior to this that his short-term memory was getting worse. I thought it may be because we were getting older?

In these earlier stages, the problems of declining function may become much more obvious in a new or challenging situation, for example with the death of a spouse or on a holiday in an unfamiliar area, in hospital or during respite care in a residential home.

I thought a holiday might help so I purchased a van and we spent four months camping along the east coast of Australia. On two occasions I lost her; once in a caravan park and on another occasion, despite my being alert, she disappeared from the beach. Fortunately on each occasion, following a search, I found her.

Losing track of the conversation topic due to memory impairment can make it difficult to hold a meaningful conversation and interact socially. People with memory problems may avoid interaction with others.

He will not seek company or mingle and crowds upset him.

Memory problems can also make it difficult for the person with Dysexecutive Syndrome to read and follow a story-line.

He does not read anymore, as he can't concentrate on the story lines, he can watch the same game of football over and over.

How are the person's problem-solving and judgment affected?

Impaired judgment and insight is noticeable. The person with the syndrome lacks an ability to realistically assess and manage the problems of everyday living. Any new problems and situations may be poorly handled.

Previous hobbies and other skills of normal daily activities deteriorate.

Then he began to lose interest in the hobbies he loved, woodworking, gardening and general pottering around. He was changing into a different person, from the clever hardworking man able to put his mind to anything.

People with Dysexecutive Syndrome may be suspicious of others. They may not be able to understand that an item is lost and blame others for stealing it. They may accuse others of taking their money or trying to sell their house.

Things get lost or stolen repeatedly; this is hard as he accuses family of taking them.

Disagreement may cause arguments. Due to their disease, the person with the syndrome may not have insight into other people's situations or to their own state. Often they don't realise that they have a problem and don't know how to initiate activity to rectify that problem.

How are initiative and insight affected?

Lack of insight often leads to a loss of social skills such as loss of normal speech and behaviour in social and group relations.

We can all see that he is finding this terrible disease hard to deal with as he has no great interest in many things anymore, which is so sad.

We found out that he was being bullied by an older man and pressured into giving him money. He didn't seem to understand that this was wrong.

What types of behaviour changes can occur?

Due to poor insight and the loss of understanding, people with Dysexecutive Syndrome may react aggressively, or appear stubborn and self-centred. It is important to remember that it is caused by the person's disease or syndrome. The person has no or minimal control over their reactions to frustrations or their lack of understanding.

Reactive aggressive behaviour may result from poor impulse control and loss of a previous understanding of what is acceptable in a given social situation.

(She) argues at the drop of a hat, always looking for an argument . . . she never cares where she is, she will try and argue with you, my last encounter was at her GP's surgery . . . at the pharmacy there was a heated discussion about her medication, apparently my mother was so rude to the people in the pharmacy.

When the interest rates went down, she stormed into the bank and accused them of doing this deliberately; she seemed to miss the point that this was a global issue.

People may become resistive or aggressive in the face of attempts to provide care as they do not recognise what is really being attempted or by whom.

At times she no longer recognised me and showering could take some time as she was sometimes very angry and uncooperative.

The frustration and his change of manner, he became quite nasty (but not violent). I have rheumatoid arthritis and other medical problems. Some days are very hard for me to deal with as his moods can be hurtful, he may be angry with me but I don't know why. This is mainly frustration on his part.

Anger and aggression may also occur (poor impulse control) as a result of loss (for example, of a driving license) and this also represents evidence of self-centred behaviour, unconcerned with the needs of others and lacking insight.

Loss of his driver's license five years ago caused ... severe anger and aggression for many years. He was almost impossible to live with.

Self-centred behaviour

Lack of insight into 'the bigger picture' and the needs of others manifests in self-centred behaviour.

They become self-centred and they are the only ones that matter, they do not worry about other people's feelings, you either have to have a very thick skin or walk away if it becomes too upsetting.

Irritable and agitated behaviour

... if I suggested that he was irrational he became belligerent. My life was extremely difficult as I seemed to be the party at fault.

I have noticed changes to her behaviour over the past couple [of years], for example, hygiene, mood swings, always on the defensive when something is suggested to her; she will not listen to reason.

Compulsive and/or obsessive behaviour

Obsessive/compulsive behaviour can sometimes be a manifestation of executive dysfunction and may indicate lack of impulse control, insight and understanding of social norms.

He is obsessive about going to the gym and used to go daily, spending over four hours working out until staff finally refused him entrance.



Helpful strategies for these behaviours



- Be aware of the likelihood of strange or inappropriate responses.
- Acknowledge the person's frustration by saying things like "That must be frustrating or annoying for you".
- Some people may retain a limited ability to reason, but wait until the person is no longer highly aroused, for example no longer angry or agitated, so they are calm if you are going to try to reason with them.
- Other people are unable to reason so don't try. Instead avoid topics which cause any upset. If already aroused, change the subject to a neutral topic, something they like to talk about, such as reminiscing about good times.
- Sometimes the uncharacteristic behaviour such as withdrawal, agitation and/or irritability may be an indication that the person is in pain, but unable to articulate this. This possibility needs to be discussed with their medical practitioner.

Effects on sleep

People with dementia, delirium or other severe psychiatric illnesses often have disturbed sleep patterns.

She was often up at night walking about. . . . was all dressed and wearing make-up, ready to go to the club.

Some will not recognise that it is night-time and may become upset when you try and correct them.

He could not recognise the time of day.

She was always phoning us in the middle of the night.

This is part of the disease or syndrome over which they have no control. Gentle exercise during the day may help promote better sleep better at night. If not, allow activity in a safe manner. The doors may need to be locked to prevent wandering. Ensure that you have a key at all times in case of emergency.



Helpful communication and memory strategies



Communicating

- Encourage conversation, and focus on familiar, reminiscent and/or here and now, contextual information.
- Find a quiet place for conversation to avoid distractions; avoid large group conversations. Give orientating information regularly in conversation. For example, "It's Friday today and at 11 am we will go to the club. It's a cold day, so we'd better wear warm clothes."
- Give gentle reminders about the conversation topic, for example, "You were telling me something about your sister? What was it you wanted to say about your sister?"
- Explain things clearly but simply. Allow time to understand what you say and time to respond.
- Check what you have said is understood and repeat or simplify where necessary.
- Use gesture (such as pointing), prompts, pictures and/or diagrams to support conversation or instructions. For example, if you want the person to comb their hair, point to the brush or give the brush to them, or leave the brush where it can be seen and used spontaneously.
- Avoid jokes where you say one thing but you mean the opposite.
- Minimise expectations of the person to remember things/events. Avoid asking questions such as "What did you do this morning?"

Memory prompts

- Provide structure by trying to keep to the same daily routine where possible.
- Point out problems gently and tactfully.
- Use memory and orientation aids such as a clock, diary, calendar, timetable, notebook (written or electronic), photo album, lists (e.g., for shopping, family names, important phone numbers).
- Read these lists together to help with planning and to avoid putting pressure on the person to remember.
- Encourage writing important things down.
- Avoid asking complex or abstract questions which require good understanding and memory.
- Assist with problem-solving by breaking the problem down into small, guided steps. Doing one thing at a time.



EFFECTS ON PARTICIPATION IN EVERYDAY ACTIVITIES

Every daily activity involves thinking processes. As you have read, many thinking processes are altered in Dysexecutive Syndrome and as a consequence, the person with Dysexecutive Syndrome will experience loss of independence in performing daily activities.

Daily activities range from basic routine tasks such as getting dressed and making a cup of tea, to managing household finances, going to work, knitting a jumper and driving a car. The person with Dysexecutive Syndrome may do an activity less well than they used to, may be able to only do parts of an activity, or may no longer be able to do the activity at all. Common feelings associated with reduced independence in daily activities are frustration, boredom, aggression and reduced self-esteem as a result of a change in being able to fulfil life roles.

Lack of initiative and insight often shows up in areas of personal hygiene and grooming, as well as in domestic and other activities.

Mum was spotless in everything she did, she always presented herself well, whereas now her clothes are always dirty and she is in denial about her bladder and bowel incontinence. (She lacks insight into the problem.)

He has to be tactfully reminded and helped to shower, wash, shave etc. which is a total change for him.

He was always so well organised. I never had to worry about anything. Now it is all up to me.

People have a need to be occupied and ultimately, this is important in maintaining health. The challenge for the person with Dysexecutive Syndrome and their carer is to continue to engage the person in activities, but within the limitations of their altered thinking processes and safety. A certain amount of creativity will be required to think about what the person with Dysexecutive Syndrome previously did on a daily basis and to adapt it to make it easier for the person to carry out activities.

- Understanding the nature of the problem is helpful. People with Dysexecutive Syndrome are often unable to learn new things and if this is the case it is best to try and cope with the situation, rather than to confront and push the person into doing things which they can't manage.
- Even the best coping strategies do not always work. Ultimately, it is the person managing each individual situation who has to use his or her judgment in that instant.

HYGIENE AND SELF-CARE

... (She) needs full-time supervision in terms of dressing, hygiene and other activities of daily living.

Any task that we perform on a daily basis involves various steps. Most of us perform these steps automatically and it's not until we think about it do we realise how many steps are involved in one particular task. For example, when you brush your teeth you collect your toothbrush, go to the sink, open the toothpaste, put paste on brush, turn on the tap, put the brush under water, brush your teeth, spit out any excess, brush again, spit out excess, rinse with water, turn off the tap, put the cap back on the toothpaste, dry your face, put away your supplies.

For someone with Dysexecutive Syndrome they may have difficulty starting, organising and following through the various steps involved. The more complex the task the more steps involved to complete. In addition, people may have difficulty within the individual steps related to judgment, insight and problem-solving.

Routine is very important and breaking tasks down into steps may assist. The person may only be able to focus on one step at a time.



Helpful strategies for self-care behaviours



- Break down the task in your head and look at each step individually, like the example given above regarding cleaning teeth.
- Providing the person with prompts — this can be in the form of telling them what to do or acting out each activity.

Using the example of showering and dressing:

- 20–30 minutes before showering ask the person if they want a shower; if they refuse tell them you will come back in 30 minutes to see if they have changed their mind. Leave towels, soap bag and clothes in a place that they can see them as this will act as a visual clue and may help with initiation.
- If you live at home with the person, have a shower before them and highlight the reasons for having your shower, for example, going out, hygiene, wake you up, make you feel better
- When performing a task leave items out where they can see them.
- If possible lay clothes out onto the bed in order that they normally put them on, this helps the person to correctly identify garments and helps as a visual cue of what to do next.
- Alternatively, hand each garment of clothing to the individual.
- Concentrate on one task at a time before moving on.
- Keep instructions simple and short.
- Reduce distraction and keep environment free from clutter and turn off TV and radio during the activity. Allow plenty of time for this task.

More generally:

- Establish a routine.
- Monitor safety –identifying safety issues may be difficult (e.g., standing to put on trousers is dangerous).
- Produce a simple logbook to keep track of money. The logbook can be to monitor daily or weekly funds.
- Encourage the use of lists.

PERSONAL AND OTHER ACTIVITIES OF DAILY LIVING

With the loss of the ability to perform everyday tasks, people experience a loss of roles, self-esteem and self-worth. This loss can contribute to frustration, boredom and aggression. Involve the person in activities they are *still able* to do.



Helpful strategies for activities



- It is important to continue to engage the person in activities. These can take the form of diversional, recreational or functional.
- Encourage responsibility and contribution to the household, no matter how small, and reinforce how helpful that person may be.
- The activity can relax or divert a person who is becoming agitated or aggressive.
- Be creative. Think about what the person did on a daily basis and adapt it to make it easier for the person to achieve.
- Make use of over-learned tasks.
- Allow a chance to express emotions.
- Avoid activities that reinforce/highlight problem areas.
- Don't put a lot of focus on completing the task, if this is not achieved the person can become agitated and have their self-esteem lowered.
- When going out think about: overcrowding, time of day, not overstimulating.

Doing the activity with the person/Doing some parts of the activity for the person

Cook the evening meal with the person and involve them in washing and peeling vegetables.

Providing prompts throughout the activity

Tell the person what to do step by step.

Write out the steps of the activity if the person is able to read and follow written steps.

It may also be important to shift the focus from completing an activity to contributing during the activity.

Often the use of activity can relax or divert a person who is becoming agitated or aggressive and can provide the person with a sense of satisfaction and fulfilment. Some examples are:

- Polishing shoes
- Sorting objects
- Watering plants
- Peeling vegetables or doing one specific cooking task
- Folding clothes/ towels
- Polishing silver
- Dusting
- Relaxation music

FEEDING, SWALLOWING AND NUTRITION

Swallowing difficulties may occur following brain injury and in the later stages of dementia. Even where there are no physical swallowing problems the person may still have problems with eating and drinking and/or meal-time behaviour. This may be due to problems with memory, initiation, problem-solving and planning skills, awareness, judgment, insight, impulse control and attention.

... (He) has been unable to manage certain foods for at least the last seven years. This includes difficulties with cutlery and swallowing and these problems are becoming progressively worse.



Helpful strategies for eating, drinking and at mealtimes



- Establishing a meal routine.
- Making mealtimes quiet in order to avoid distractions.
- Orientating to meal and utensils if necessary (“here’s your lunch, you have chicken, pumpkin and peas.”)
- Offering small portions at a time, one course at a time or encourage eating most of one food before moving to the next to avoid confusion when the taste and texture changes.
- Offering bright and colourful food and making sure food is visible.
- Ensuring dentures are fitted where needed.
- Encouraging the person to be involved in preparation of food and drink where possible.
- Supervising mealtimes while promoting independence as much as possible.
- Where necessary, giving clear and tactful verbal prompts to slow down eating or drinking or remind to keep eating, drinking, swallow, or finish the meal.

Where there is a diagnosed swallowing problem, ensuring any swallowing guidelines are followed, such as giving the person the recommended modified diet and fluids or using specific feeding or swallowing techniques.

- Using modified utensils if required. Seek advice from an Occupational Therapist if necessary.
- Contacting a dietician if there are concerns about nutrition, for example significant loss of weight, or a reduced range of food types being eaten.
- Contacting the treating medical specialist or general practitioner if there are concerns about swallowing, for example if the person is coughing, choking and/or gagging when eating and drinking or has recurrent chest infections.

MOBILITY

Walking and moving about are not usually impaired in the early stages of the syndrome. As the syndrome progresses people can become prone to falling and have difficulty modifying their behaviour to allow for the changes in their balance. Immobility can occur in the final stages of this syndrome.

It is important for all involved that walking ability is maintained for as long as possible. This can decrease the amount of care required, and also improve quality of life. Outings can be shared and independent personal care sustained.

Regular walking in familiar routes may help to relieve frustration and use up excessive energy, and help normalise sleeping patterns. Exercise can act as a distraction when the person becomes frustrated with unproductive activities.



Helpful strategies to maintain mobility



- Keep to old routines such as regular walking along familiar routes.
- Make sure the environment encourages the person to move easily and safely.
- The bed and chair height should be adjusted to make standing easier, and ensuring that the furniture is stable or firm.
- Ensure adequate lighting, especially at night, and that pathways are clear.
- Avoid noisy, complex or busy environments if the person is easily distracted.
- Cues or prompts may be used to help with safety (e.g., “hold onto the rail”), support their arm when walking over rough surfaces etc.

A note on driving

Driving is one of the most complex daily activities and safe driving is hugely dependent on adequate reaction times, quick judgment and problem-solving.

Drivers are obligated to alert the state licensing authority of any health changes that may affect their ability to drive safely. The person with Dysexecutive Syndrome may be an experienced driver with a long, safe driving record and may insist that, “I’ve been driving for fifty years and never had an accident . . .” displaying poor insight into the situation. This can be very difficult for family members who may be very concerned about that person’s ability to drive safely. Driving is very important to many people to maintain their independence within the community, but it is a privilege and a responsibility and not a right to drive.

The person’s general practitioner (GP) will help decide if the person with Dysexecutive Syndrome is medically fit to remain driving. If the person is medically fit, the GP may refer to a specially trained occupational therapy driving assessor for an assessment of the person’s driving. If the person is not medically fit, the GP will organise to have the person’s driving license cancelled with the state licensing authority.

FINANCIAL MATTERS

One of the greatest stresses to the person and their family and friends is often a practical one. The affected person's day to day affairs may have become very disordered as bills are left unpaid because the person is unable to organise their payment.

Our income was suddenly and immediately reduced by two thirds.

She was always very careful with money, she could account for every cent that she spent, whereas now, she wastes money on stupid things, (e.g., making unnecessary phone calls, local and interstate; will buy meals on wheels but is hardly ever home to eat them).

He was running out of money and refusing government assistance, even though he could sell his very expensive house and buy a less expensive one.

In the early stages of the onset of Dysexecutive Syndrome it is important for the person affected to put in place an Enduring Power of Attorney, which empowers a person or persons they trust to manage their affairs when they are not able. You can contact the Hobart Community Legal Service for advice on 6223 2500 or you could contact a solicitor.

If the person affected is judged by medical staff as no longer having the capacity to make decisions then it will be necessary to contact the Guardianship and Administration Board on 6233 3085. They can appoint one person out of the affected person's family or friends to administer financial matters, however if no one is able to take this responsibility on, or it strains relationships with family and friends they can appoint the Public Trustee to manage the person's financial affairs.



WHAT DO CARERS OF A PERSON WITH DYSEXECUTIVE SYNDROME EXPERIENCE?

Obtaining diagnosis

The importance of an accurate diagnosis to family/friends/carers must be appreciated.

Diagnosis provides the basis for understanding a condition and allows for more rational management plans and, for some disorders, genetic counselling, even when a specific medical treatment or cure is not currently available. At times, an accurate diagnosis may not be made until the disease or syndrome is advanced due to the subtle symptoms of the condition.

Accurate diagnosis can link the affected person and their family to the specific support services.

There was a huge problem in gaining a diagnosis ... I noticed behavioural peculiarities about a decade before diagnosis ... there was no family history of Huntington's disease developing ... [it was] helpfully suggested that we "return in twelve months to see if symptoms had progressed".

Diagnosis and test results took several months.

... visits to doctors increased, as did visits to practitioners of alternative medicine. The medical tests increased and a year later we received the results of a visit with the announcement 'It is Alzheimer's Disease!'

I perhaps, intuitively, felt there was something seriously wrong but refused to accept this, as it is usual to fear the worst.

Referral to specialists may assist.



Personality change

Sometimes it is difficult for family or friends to identify where long-term character traits and personality quirks end and dysexecutive features begin. A degree of disinhibition can happen to all of us, for example, if we have drunk too much alcohol. There can be an unmasking of less obvious traits or, commonly, an accentuation of the person's traits. In the latter situation, a person almost becomes a caricature of himself or herself.

How do I recognise the difference between a person suffering from Dysexecutive Syndrome from their normal personality?

... she is a very manipulative person.

Disinhibition and embarrassment

Disinhibition or lack of impulse control may present as anger, tearfulness, excessive singing or talking or inappropriate sexual activity. The disinhibition is due to damage to the brain and not the person's usual behaviour. This can be very upsetting for the carer or family/friends, especially if the disinhibition is of a sexual nature.

I feel one of the greatest difficulties is embarrassment caused by the many situations ... [He is] completely oblivious to the embarrassment and blames me for the consequences.

It can be embarrassing taking Mum on an outing. [She makes insensitive remarks as a result of disinhibition and self-centred orientation.]

Inappropriate behaviour can become very embarrassing when taking my mother on an outing, for example whether it is for a doctor's appointment or shopping trip the insensitive remarks she makes to people who are trying to help her, the way I can best explain it, is like a two-year-old child, if it cannot get its own way, it stacks on a turn ...

Sharing information with others may be the best way to maintain the person's dignity and help others to respond with understanding, rather than react to aberrant behaviour.

Role, lifestyle and relationship changes

Gradually, without any nursing training, I became responsible for showering, toileting, dressing my wife, in addition to cooking, making hospital visits and coping with increasingly difficult behaviour.

The most traumatic and worrying thing is that we have adult children who have to deal with the question of knowing their genetic predisposition to Huntington's disease or not.

As I am at work all day, I need to spend many hours of time-consuming preparation and planning daily to ensure [he] retains comfort and normality in his everyday life.

... my dad has a bit of a memory problem. I know that sometimes he does not have a clue who I am, just that I mean something to him and that I love him very much.

My life was extremely difficult as I seemed to be the party at fault.

She has become more challenging to other family members, carers, doctors etc.

We can still have a laugh together as he still has his sense of humour, but sometimes I have to be like a parent to him as I am the one who can get away with bullying him into doing things.

Phases of illness

Phases in the evolution of Dysexecutive Syndrome, such as with progression of dementia or other diseases, may be evident in many cases.

The disease, I would estimate, took about thirteen years to kill my wife. Initially, there was a period of uncertainty, questioning and concern at her loss of control. This was followed by a period of calmness, with dependence on me, her carer. Finally, there was a rapid period of deterioration, culminating in the need for total care, which could only be provided by the Nursing Home.

Note in many dementing disorders the initial phase is the most troubling as the person with dementia often has some insight.

The changing routine was gradual, so I accepted it as normal. It placed no great pressure on me and my lifestyle and my wife appeared contented. I later learnt from her secretary of my wife's request to arrange a doctor's appointment.

... she experienced three seizures, the first two at home ... and another on arrival at hospital. The hospital specialist told me that it was time for my wife to be placed in a Nursing Home. Although upset, I felt enormous relief, as I could not have made that decision.

Coping

Dysexecutive Syndrome can have a significant impact upon the family and friends of those affected. The change in the person affected can strain the relationship between the person and those close to them. As you will have read elsewhere in this booklet the person's personality may alter and they may view caring actions by family and friends with suspicion or even abuse.

Family are gradually accepting things with dad but it has been hard.

I try to be tolerant and have patience with her, but it wears thin after a while.

At the end of the day, I cannot see it becoming any easier, as my mother is only getting worse, all we can do is try and support each other as much as we can, and try and help our mother and make her as comfortable as she will allow us.

It takes a lot of patience to understand it is a condition he would not want to have. As a wife and a carer I have to be aware constantly that everything is switched off and locked, like you do with your children although I have to be alert 24/7.

I have found some family members cannot come to grips with it as to them he is not their dad as they remember him and they withdrew a little.

It worries me very much that I don't know how long I will be able to look after my dear husband, but I will do so as long as I am able.

Unless you have support from your family, life becomes very difficult.

We can't go to the type of social events that we previously enjoyed although we still have some very loving family and friends.

Pets may have a settling and soothing effect for someone with Dysexecutive Syndrome.

He has a little dog that he loves dearly. The small amount of exercise he does get is to take the dog for short walks. I think animals are very good therapy.

HELP FOR THE FAMILIES, FRIENDS AND CARERS

Health care/medication

There are some medications that may be useful in alleviating the troublesome symptoms of Dysexecutive Syndromes and/or the underlying brain condition. Symptoms, which may be responsive to treatments with medications, are anxiety, depression, erratic mood swings, anger, irritability and excessive crying. Psychotic symptoms (delusions, fixed and false ideas or hallucinations such as seeing, hearing, smelling or feeling things that are not real) may also be treatable.

[He was] prescribed an antidepressant about 2 years ago and I feel that his drug should have been prescribed earlier.

Social networks and supports

Changes in sufferer's behaviour and their abilities in daily activities can be chaotic and distressing. There is currently no cure for the vast number of illnesses which cause Dysexecutive Syndrome. Many families find themselves hiding the condition of their relative, either consciously or unconsciously, feeling some level of embarrassment and responsibility. However, if you can be honest with your family and friends about the person's condition and the changes that are happening and which may happen, you give people every opportunity to adjust to the change and understand it.

Dad likes to know where mum is at most times, so if mum has appointments I try to go to their place so that dad is not left alone and then mum can have a bit of time to herself and take time out. He does not like to leave home except to take his dog for a walk. His chair is his island and safety zone.

... he likes to stay at home and hates me to leave him. Quite often I feel the walls closing in on me, I realise he is afraid and cannot understand what is happening to him. We are extremely thankful for the help and support of the local community nursing centre and our dear family.

I am constantly hurt by the absence of our former social network, which makes me feel that we've lost our status in the local community.

... member(s) of the family are worth their weight in gold ...

... the support I get from a handful of trusted friends who know the family background, is great, I don't know what I would do without their support.

There are a variety of community support organisations, some of which are specific to the disease causing the Dysexecutive Syndrome. See Suggestions for Support Services.

PLANNING FOR THE FUTURE

Individuals with Dysexecutive Syndrome, their family and friends may wish to consider planning for the future. This may involve considering what is important to you in terms of future medical treatment and other lifestyle decisions, as well as management of financial matters. It is important that individuals consider these issues while they have the capacity to make decisions.

The Royal Hobart Hospital supports advance care planning and encourages hospital staff to engage in discussions with patients and their family/friends in order to plan for future care. This may involve appointing someone as your Enduring Guardian and/or documenting your wishes for future medical care and other important matters.

SERVICES IN THE COMMUNITY

You must not be afraid to ask for help because you frequently need comfort and backup.

Caring for people with Dysexecutive Syndrome (DS) is potentially (and often is) stressful. The many needs of the carer must be considered and addressed. Often families will become isolated through the demands of caring for the person with DS and many people find it difficult to ask for help until the caring situation reaches crisis point.

... I rang in desperation ... a ... counsellor and she arranged one day's respite care each week at an excellent facility ... and this I greatly appreciated.

For those who are caring for someone with Dysexecutive Syndrome, it is important to monitor stress levels, ask for help if you need it and to receive support and 'time out'. Maintaining time and activities that you enjoy will be vital to you being able to keep going as a carer. **Looking after yourself will make you a better carer!**

Try to maintain your own interests to give you some respite. Continuing to work may help you keep a grip on reality and sanity.

The specialist made himself readily available, family and friends frequently give their time and this enabled me to lead a 'normal life'.

It is important to know that there are many support services that will be willing to assist you and the person you may be caring for, and that you do not have to be in crisis to receive support.

The local Huntington Disease team were very supportive. An invaluable resource and confidante ... has organised services such as physiotherapy, speech therapy and consultations with specialists.

Another great resource has been [his] GP who is available to talk to me and help me resolve some difficult situations.

We are forever in debt to our doctors who have cared and helped us so much.

SUGGESTIONS FOR SUPPORT SERVICES

The following services may be useful in supporting you:

- Aged Care Assessment Team (ACAT) — assesses for in-home support, respite and residential care Phone: (03) 6222 7274 (Hobart)
- Alzheimer's Australia (TAS) — operates as an information, education, counselling and referral service for people with dementia, their families and caregivers.
Phone: 1-800 100 500
- Association of Friends and Relatives of the Mentally Ill (ARAFMI) — a group of people who have a close family member or friend with a mental illness, who work together as volunteers to support others in a similar situation. Phone Help-Line: (03) 6224 7247 All hours (24hours per day)
- Brain Injury Association of Tasmania — works to promote issues related to Acquired Brain Injury (ABI), raise awareness of brain injury and reduce the incidence. Its aim is to improve the quality of life for people with ABI in Tasmania. Phone: (03) 6278 7299
- Carer's Association of Tasmania — provides information, advice and support for carers. Phone: (03) 6231 5507 (Hobart), 1-800 242 636 (Commonwealth Carer Resource Centre)
- Commonwealth Carer Respite Centre — aims to support carers by facilitating their access to respite care, information and other forms of support or assistance, according to the needs and preferences of the carer. Phone: 1-800 059 059
- Contact your Solicitor or Hobart Community Legal Service (Phone: 03 6223 2500) are available for financial advice about Enduring Power of Attorney.
- Disability Services — provides Syndrome assessment, information and education, respite care, short-term support, service coordination, resource support, day options and longer term accommodation for some clients. Phone: (03) 6230 7600 or 1-300 799 530
- Headway Support Service — HSS is a specialist community based rehabilitation service for people with disabilities, specialising in working with people with acquired brain injury (ABI), their families and social networks. HSS supports people to rebuild their independence through the development of their skills and abilities across their physical, social, academic, vocational and personal life domains. Phone: 1-300 138 296
- MS Society — offers counselling and support services to people with MS, their family and friends. They also offer an immunotherapy education service, support groups, a resource library, internet access and case management. Phone: 1-800 676 721
- The Tasmanian Huntington's Disease Association — provides Syndrome education, information and support to people with Huntington's Disease (HD), their carers and families, those 'at risk' of developing HD and the broader community. Phone: (03) 6431 3403
- If there are difficulties with who will be making health and living arrangement decisions contact a Social Worker. Assistance from the Guardianship and Administration Board may be needed. Phone: (03) 6233 3085.

These services may be very useful to you, but time and again it is the informal supports to you and the person with Dysexecutive Syndrome that seem to make the difference. Don't be afraid to call on family and friends to share the load.

*All details were correct as at May 2008



APPENDIX

Sincere thanks go to the following individuals from the Royal Hobart Hospital for their contributions to this booklet.

Rosalind Burgess - Senior Speech Pathologist

Jane Davis - Clinical Nurse Specialist.

Jennie Delaney - Deputy Manager Physiotherapy

John Hooper - Senior Social Worker

Nicky Kay - Senior Occupational Therapist

Ka Hi (May) Mak - Senior Dietitian

Dr Janine Martin - Clinical Psychologist

Kerry McKiernan - Occupational Therapist

Dr Frank Nicklason – Physician, General & Geriatric Medicine

Dr Rob Thornton - Clinical Nurse Educator

Judy Voute - Clinical Nurse Manager

Kathleen White - Physiotherapist

INSIDE BACK COVER

BLANK

BACK COVER

BLANK