



کلیک کنید PDF برای فایل
به کانال تلگرام ما به پیوندید



این مقاله توسط عده ای از مراقبین اف تی دی از سراسر دنیا تهیه شده و توسط آقای گلن دیویس Glen Davis ویراستاری شده است. اطلاعات جامعی که در این مجموعه گردآوری شده است، عموماً برای مراقبت از بیشتر بیماران مبتلا به انواع دمانس، قابل استفاده میباشند. لینک های بسیاری که میتوانید دربرگیرنده جواب سوالات بیشتر مراقبین دمانس باشند در آن گنجانده شده است.

در حال حاضر، این مقاله را عیناً برای استفاده کاربران وبسایت دردانشنا که به زبان انگلیسی آشنا هستند، در بخش منابع و مراجع قرار داده ایم. در نظر داریم قسمتهایی از این مقاله را که مورد نیاز بیشتر مراقبین فارسی زبان است، در آینده به فارسی ترجمه نموده و در همین بخش بارگذاری کنیم.

با تشکر فراوان از گردآوردندگان مجموعه پیش رو، مخصوصاً آقای گلن دیویس.

AFTD's FAQ page addresses some of the most frequent calls to their help line. I can see why they may not want to broaden the scope.

The additional subjects which I believe should be compiled for use by carers and families are:

Diagnosis

The diagnosis of any dementia is presently conducted by the observation of symptoms. Confirmation of the diagnosis is possible only by post mortem examination. Because many symptoms are displayed only intermittently and may be suppressed outside the patient's everyday environment, a diagnostician should give attention to the observations of family members. This aspect of diagnosis is most difficult for the behavioural variant of FTD, particularly if the patient exhibits anosognosia. A practitioner with personal history of the patient's past behaviours will have much better comparison and therefore stronger basis for accurate diagnosis.

For many different reasons, a practitioner attempting to diagnose cognitive disorders in a patient may not have personal long term knowledge of the patient's symptoms nor the trends over a period of time. A carer

can help with observations, notes and examples, written briefly and submitted confidentially in advance of a diagnostic appointment.

Sometimes, a patient (especially those exhibiting anosognosia) will be reluctant to attend or cooperate in diagnosis. There are suggestions including referrals that can usually help. See <http://ftdsupportforum.com>

<http://brain.oxfordjournals.org/content/132/5/1299>

<http://www.bmj.com/content/347/bmj.f4827>

Wills, powers of attorney, insurance, finances

These legal preparations should be conducted at the earliest opportunity. In the event that a diagnosis is subsequently reached, the competence of the patient then comes under a cloud and decisions including wills may be difficult to reach or subject to later challenge. An elder care attorney can assist with these subjects.

There is a lot at stake. Patients with dementia can lose judgement and inhibitions and there are too many very sad stories of retirement savings and other family assets given away, gambled or squandered before the trend was detected. There are many concrete suggestions regarding insurance and bank account access on: <http://ftdsupportforum.com>

<http://www.lentillem.com/columns/>

Communications with FTD patients

Most patients with FTD suffer decline in communications abilities. With each of the aphasias and with the semantic variant ("semantic dementia"), communications disabilities are among the earliest symptoms of dementia and are likely to become severe disabilities during the mid-stage of the disease's progression. Symptoms may present first in expression, with symptoms in comprehension being more difficult to observe until they become more pronounced. Disabilities in expression most commonly appear as difficulties in finding words. A patient may have difficulty finding some nouns, or make pronoun errors (using "he" for "she") or be unable without prompting to come up with the names of friends. Because family members help the patient with these expression difficulties, they may go unnoticed and undiagnosed for some time. By a couple of years in, if not sooner, s/he will begin losing the concept of what that word means and lose comprehension of sentences.

<http://www.alzheimersreadingroom.com/2010/03/ten-tips-for-communicating-with.html>

Adaptive clothing

Dementia patients often encounter difficulties with simple daily tasks such as dressing. Buttons and zippers are often the first examples of failures of executive function. The lives of the patient and carers can be assisted by the selection and purchase of suitable adaptive clothing with simplified closures and fastenings.

Get iron on names tags for all their clothes and include your home number on the tag.

<https://www.label-land.com/cart/>

Sources of Adaptive Clothing:

<http://www.buckandbuck.com/>

<http://petalbackclothing.com.au>

Loneliness

For many dementia patients, loneliness is the worst of outcomes. It can occur for multiple reasons. Some patients avoid social contact, concerned about displaying any disability to people who may not be understanding or aware. Some friends and family members, especially those with infrequent contact with the patient or with no previous experience of dementia, may not observe the symptoms. "He seems fine to me!" is a common observation. These factors result in the increasing isolation of the patient and the carers, as their active community shrinks. Many spouse carers live in isolation with their LO who are not able to provide them with company, conversation or emotional support.

Consider relocation during the early stages, closer to family members able and willing to be part time carers.

Build support networks to provide part time care and allow the principal carer more social interaction.

<http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3181916/>

<http://community.seattletimes.nwsourc.com/archive/?date=19970729&slug=2551917>

http://www.nytimes.com/2010/04/11/fashion/11LOVE.html?pagewanted=1&_r=2&adxnlix=1290369711-km5/lojJ5H8F2sUAKiBU7g

Shrinking community and back turners

For some families dealing with dementia, the worst aspects of loneliness are weakening relationships and lack of support from some family members, from their congregation, or their former close friends. These are the most keenly-felt aspects of FTD isolation.

It is a gift that the principal carer can offer to "back turners", to invite their part-time participation in the care of the patient. Even to send them broadcast email updates can keep them aware of the status and the issues being addressed. It is easy and common for some small family rift to become exaggerated by the stresses of the dementia journey. Small measures to keep communication open can close the gaps and pay big dividends.

<http://www.washingtonpost.com/sf/post-live/collection/caregiving/?hpid=z5>

Asking for help

No carer can provide unassisted 24*7 care of an FTD patient indefinitely. Eventually, some aspect of the health or fitness of the carer will require assistance. Carers need to arrange for their respite. They should ask before the need becomes desperate, to allow relationships to be built.

The oldest and best forms of respite are from other close family members, who know the patient. They are most readily recognised and accepted as sources of assistance for the patient in some intimate requirements such as dressing and showering. Sometimes, "authority figures" such as a nurse in uniform, or a doctor or home care worker, can achieve what even family members cannot. A prescription for showering, bathing in medicinal salts, or not driving may greatly help achieve the necessary outcome.

<http://www.mayoclinic.org/healthy-li...06%2f2014&pg=1>

www.thealzheimerspouse.com

<http://www.geripal.org/2013/12/the-dementia-caregiver-improving-their.html>

<http://psychcentral.com/blog/archives/2011/03/27/8-survival-tips-for-the-spouse-of-a-terminally-ill-person/>

Activities for the patient

FTD patients often lose abilities to type, operate remote controls, use door latches, fasten seat belts etc. These executive functions and sequences become disabilities when the disease attacks the frontal lobe of the brain. Finding activities to keep patients occupied can sometimes be easy. Some become absorbed by Sudoku, TV or dictated emails. For others, satisfying activities can be a big challenge for the carer.

<http://ftdsupportforum.com/showthread.php?t=21000>

<http://ftdsupportforum.com/showthread.php?t=15334>

<http://ftdsupportforum.com/showthread.php?t=11300>

<http://ftdsupportforum.com/showthread.php?t=2030>

Safety, hygiene, continence and showering

Caring for a Spouse with FTD.

<http://www.youtube.com/watch?v=xRee-WPBoCQ>

<http://www.youtube.com/watch?v=AOBPNy7eQcY>

Bathing and Dressing: Caregiver Tips

<http://www.youtube.com/watch?v=lvQtjY3-bcE>

Toilet and Incontinence.

<http://www.youtube.com/watch?v=4DvYE12CM0c>

Nutrition.

<http://www.youtube.com/watch?v=hrNpX913KkE>

Safe At Home.

<http://www.youtube.com/watch?v=uSUNMbQz59g>

<http://ftdsupportforum.com/showthread.php?t=18614>

Anosognosia

(Patient lack of awareness of decline or difficulties) "not denial"

Books, movies and videos

<http://www.youtube.com/watch?v=SkXQZusfjm4>

Videos:

What is life like for someone with FTD?

http://www.youtube.com/watch?v=m0VOv_ZV-Xc

Early Onset Dementia.

<http://www.youtube.com/watch?v=2iHUXSVv8Mg>

Symptoms and stages

http://www.caring.com/articles/activities-for-alzheimers-and-dementia?utm_campaign=alz%3Aearly_moderate_memory%3A9&utm_source=stages

Experts Redefine Dementia as a Terminal Disease -
TIME <http://content.time.com/time/health/...#ixzz2ufauVG61>

<http://www.nextavenue.org/article/2014-01/special-series-under-60-and-living-dementia>

<http://www.dementiaguide.com/symptomlibrary/>

Medication

DRUGS

<http://ftdsupport.com/side-drugs.htm>

At present, there are no medications approved specifically to treat or prevent FTD and most other types of progressive dementia. However, sedatives, antidepressants, and other medications may be useful in treating specific symptoms and behavioral problems associated with these diseases.

There is a list of medications to avoid with FTD.

<http://memory.ucsf.edu/ftd/overview/...ications-avoid>

To research drugs considered for FTD patients:

www.drugs.com

www.rxlist.com

www.cymbalta.com

www.webmd.com

<http://alzheimers.about.com>

<http://ftd.med.upenn.edu/>

Empathy and blame of carers

<http://www.youtube.com/watch?v=hVjltYNgU6s>

(Documentary on Empathy)

Driving with dementia

Starting the Conversation:

<http://www.youtube.com/watch?v=FWTCKdpwdTc&list=UUkoC3cZOPXN3ISf9p3JcoPQ&feature=c4-overview>

Staying Connected:

http://www.youtube.com/watch?v=L0naXHSU_MA&list=UUkoC3cZOPXN3ISf9p3JcoPQ&feature=c4-overview

<http://www.bidmc.org/CentersandDepartments/Departments/Neurology/CognitiveNeurology/Drivewise.aspx>

Carer relief and respite

<http://www.youtube.com/watch?v=YDDSk-L-R90>

Screening and testing (including genetics)

<http://psychcentral.com/blog/archives/2011/03/27/8-survival-tips-for-the-spouse-of-a-terminally-ill-person/>

ADDENBROOKE and ACE-R, among useful tests for dementia symptoms

http://www.stvincents.ie/dynamic/File/Addenbrookes_A_SVUH_MedEl_tool.pdf

<http://www.ftdrg.org/ace-r-download/frontotemporal-dementia-rating-scale-frs-download/>

Research on testing:

http://journals.lww.com/neurotodayonline/Fulltext/2009/06180/Progress_on_Frontotemporal_Dementia__A_Blood_Test.10.aspx

Genetic Testing

One of the conclusions of the 2015 Vancouver FTD conference was that there are more discoveries to be made in the genetic factors contributing to FTD. Also, there are other wholly unknown trigger factors at play which determine whether, in the presence of a genetic abnormality, FTD develops. So there is a great deal yet to be learned.

Still, the consensus of practitioners is that the majority of FTD cases are sporadic.

Huge ethical issues arise for carers researching the genetics of a FTD patient. Implications extend to the patient's siblings and offspring. Every autopsy, every tissue donation and every piece of research into the causes of FTD can lead families into the knowledge that genetic factors may put them at greater risk. Genetic counselling should be available to and sought by every carer and FTD patient involved in any FTD research.

<http://www.theaftd.org/wp-content/uploads/2009/02/Final-FTD-Genetics-Brochure-with-Cover-8-2-2012.pdf>

<http://www.theaftd.org/frontotemporal-degeneration/genetics/talking-about-genetics-with-children>

Genetics:

http://www.cerebralfunctionunit.co.uk/newsletter_archive.html

<http://www.cerebralfunctionunit.co.uk/2011%2009.pdf>

<http://www.ftdrg.org/caregivers/ftd/genetic/>

<http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2352148/>

Choosing ALF and NH residences for patients

<http://psychcentral.com/blog/archives/2011/03/27/8-survival-tips-for-the-spouse-of-a-terminally-ill-person/>

<http://www.marketwatch.com/story/10-...8?pagenumber=1>

PLACEMENT

Checklist for selection:

<http://www.agis.com/Document/2/alzhe...checklist.aspx>

TIME FOR PLACEMENT

<http://ftdsupportforum.com/showthread.php?t=25255>

Children in the family

<http://research.baycrest.org/files/F...etectives-.pdf>

http://www.thestar.com/life/parent/2..._a_parent.html

<http://memory.ucsf.edu/ftd/community-support/support/ftd/multiple>

Holidaying with an FTD patient

<http://www.sheridanseniorcenter.org/publications/CenterStage-112208.pdf>

Hospice

<http://www.momentsoflife.org/content/hospice-helps-people-live-best-they-can>

http://www.theaftd.org/wp-content/uploads/2011/10/Hospice-and-FTD_Hospice-of-the-Valley-2011-ppt-online-version.pdf

Gone From My Sight, Barbara Karnes RN.

<http://www.youtube.com/watch?v=PPx-qpos57g>

Dementia: End of Life Care.

<http://www.youtube.com/watch?v=3zKADdgc14>

Grieving and renewal

"Relearning the World" by Brooke Davis. "Grief is not neat...it does not end; it is not 'resolved'. It does not follow a checklist of emotions from beginning to end. It is not one thing, or the other thing; it is lots of things."... "...grief is now, simply, a part of everything I do, everything I say...everything I am."

<http://psychcentral.com/lib/the-5-stages-of-loss-and-grief/000617>

http://www.helpguide.org/mental/grief_loss.htm

<http://ftdsupportforum.com/showthread.php?t=13990>

<http://ftdsupportforum.com/showthread.php?t=14458>

<http://ftdsupportforum.com/showthread.php?t=18649>

Recovery and renewal:

Grieving is a process, a journey. The final stages of grieving a traumatic loss are recovery and renewal. For the loss of a person suffering a terminal illness, the initial losses are incremental and spread over the stages of the disease.

Those suffering from a bushfire or terrorism etc. have a distinct, frightful traumatic event that starts their process. They have a pronounced phase of high adrenalin. And they have a community of victims with some shared experiences.

Our grief journey starts in tiny steps of recognition of small losses, incremental progression, diagnosis and degeneration. It is a long time before we get some understanding of "living bereavement" and "ambiguous grief". And our journey is personal, intensely individual and inherently isolating.

We go through the same processes, the same steps, the same slow journey. And in the end, for the survivors, there is the same recovery and renewal. But it just struck me and I wanted to share... there is good news! That truly awful process that we call living bereavement has a silver lining. We can start our recovery earlier. In fact it is impossible to ignore the early progress on our grieving journey.

We do our wills and our powers of attorney. We do our advanced care directives. We make our decisions about "do not resuscitate". We suffer the many losses of the progressive, terminal diseases called frontotemporal dementia. So we are prepared somewhat. There are still surprises for us in dying, in death, in what follows. But we have already made much progress on grieving.

The good news is this. Our recovery starts earlier too. And if we can only choose the healthier processes over the dysfunctional alternatives, our renewal can be accelerated too.

Dr Rob Gordon is a registered clinical psychologist. He was in general practice before he specialised in the psychology of major traumatic public events. Here is his summary of the grieving processes. When you are ready to think about this subject, I commend his thoughts to you.

http://www.bushfirerecovery.tas.gov.au/__data/assets/pdf_file/0018/201276/Rob_Gordon_presentation_Tasmania_July_2013.pdf

Major Research Sites:

<http://www.ftlda.org/>

www.ftdsupportforum.com/

<http://www.ninds.nih.gov/disorders/picks/picks.htm>

http://www.ehow.com/about_5432526_temporal-lobe-diseases.html

<http://www.theaftd.org/about>

<http://www.hbo.com/alzheimers/index.html>

<http://www.ftdsg.org/>

<http://www.neura.edu.au/frontier/carers-patients-volunteers>

<http://www.youtube.com/playlist?list=PLAwhBH-4GO5gA5pLQhvJTgywVpNyP70Tb>

<http://www.alzforum.org/all-news>

<http://www.dasninternational.org/>

<http://www.alzbrain.org/pdf/handouts/2009.%20behavior%20book.pdf>

This is a printable booklet, helpful for family members.

http://lifeandminds.ca/whendementiaisinthehouse/ts_home.html

<http://www.cerebralfunctionunit.co.uk/information sheets.html>

http://www.cerebralfunctionunit.co.uk/ftld_overview.html

<http://www.nia.nih.gov/alzheimers/publication/frontotemporal-disorders-resource-list>

http://memory.ucsf.edu/sites/all/files/download/MAC_FTD_Primer.pdf

This is a printable booklet, helpful for family members

<http://ftd.med.upenn.edu/>

<http://visual.ly/dementia-global-epidemic>

<http://www.alz.co.uk/research/statistics>

Glen Davis

February 2016

www.dardashna.ir