HOW TO SUPPORT

THE MENTAL HEALTH

OF PEOPLE WITH

ADOA AND ADOA-PLUS

CONFIDENCE
INDEPENDENCE
FULFILMENT
SELF-WORTH
APPRECIATION
SUPPORT
ACCEPTANCE
PERSPECTIVE
OBJECTIVE
EMANCIPATION
SELF-REALISATION

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Who is this brochure for?

This brochure is aimed at care professionals who are supporting a client with the mitochondrial disorder ADOA or ADOA-plus. This condition often causes severe visual impairment (ADOA), but can also lead to a wide range of other physical symptoms (ADOA-plus). Energy metabolism in key nerve cells is disrupted, causing them to lose their function. This has far-reaching consequences for clients' day-to-day functioning and impacts their mental and psychological wellbeing. Clients with ADOA therefore often go through a grieving process as a result of a permanent loss of life opportunities.

Grief

Put simply, grief is caused by loss. Within the ADOA community, loss is experienced in every aspect of life. It is not only the loss of sight, but also the loss of a career, identity, relationships, independence... the list goes on. That is why jointly examining and exploring experiences of grief in your conversations with your client will serve as a guiding principle for your time together.

ADOA clients often speak of grief as part of their own journey towards learning to cope with their disabilities. As therapists, we know that the path to acceptance and finding new meaning is not without its twists and turns. For people with a chronic disability, we often speak of recurring grief and 'living loss'. By this we mean that the loss is a daily reality and can intrude at various, unpredictable moments. At times it is more intense, at others less so. It is an ongoing process of 'saying goodbye': to health, physical functions, relationships, expectations and a vision of the future.

We know that it is not our role to talk away grief and sadness. Our role is to bear witness, to refrain from judgement, and to walk that difficult path alongside the client.

Do's

- Welcome and offer help – Put the client at ease. Show the client around the office.
- Be flexible with appointments. Offer video consultations. Be flexible regarding charges for late arrivals or cancellations.
- Help them find local resources
- Encourage connection with support groups and peers
- Don't be afraid to ask follow-up questions.
- Recognize that the process is not linear
- Listen rather than just hear. Ask reflective questions to fully understand the client.
- Be open to the idea that not all problems are related to ADOA
- Offer validation rather than pity
- Involve sighted support workers where appropriate and with consent
- Be alert to unhealthy coping mechanisms such as substance use
- Challenge your own assumptions

Don'ts

- Refer to the client as a 'patient'.
- Trying to anticipate the client's needs. For example, physically guiding the client without asking for consent.
- Referring to family members as "caregivers".
- Raising the volume of your voice
- Attributing more limitations than there actually are. Praising achievements based on their example. Do not praise based on assumptions about what is "difficult".
- Telling clients that they are "so strong". Recognize adaptive choices and the benefits they bring.
- Being too quick to bring up your own experiences in an attempt to connect and build rapport. Pay close attention to where clients are at.
- Being afraid of humor once a good relationship has been established

Protective factors

- Family members who also have ADOA
- Early diagnosis
- Access to therapy within the first two years
- Being able to rely on a supportive community
- Access to adjustments/services at school or work
- Accessible public transport

Teenager with ADOA

For teenagers with ADOA, this condition is often the reason they first come into contact with therapy. You should therefore explain clearly what therapy is and isn't. At the start, pay particular attention to building a safe, trusting relationship.

Teenagers are told all day long what they should and shouldn't do. That is precisely why they benefit greatly from someone who really listens. Give them the space to tell their story at their own pace and to explore their feelings.

Adolescents generally possess a natural resilience. They are surprisingly adaptable, especially when they realize that positive changes are also possible. Structure, attending school and a regular daily routine help them regain a sense of control over a situation that feels beyond their control.

Sometimes extracurricular activities are cancelled. It can be helpful to point young people towards adapted sports or arts programmes.

Set clear, achievable goals by working with the client and their family to draw up a sound support or treatment plan that is regularly reviewed and adjusted. Also consider involving a counsellor or support worker from national support organizations. Humor, including black humor, often proves to be a helpful outlet. Let the young person take the lead in this.

It is useful to work together to identify strengths, such as creativity or solution-focused thinking, which your client can draw on when facing new challenges. Help them to recognize and articulate their qualities. Check with your client whether they have received sufficient explanation and information about ADOA and, if necessary, help them to find good, reliable information (https://adoa.eu/en). Focus on assertive communication and how they can explain their situation to their peers. Friends are incredibly important at this age, so ensure that social contacts are maintained and support them in building new ones.

Young adults with ADOA

For young adults, ADOA often strikes just as they are about to start building their lives. Plans for study, work or independence are suddenly derailed. The greatest fear at this stage of life is often isolation. They feel that their peers no longer understand them or think they are strange.

It is important to pay attention to energy levels. As a result of ADOA, many activities require far more energy, meaning choices have to be made about what a young adult can manage in a day. This can clash with the fast pace of their peers, which may be at the expense of social connections and can reinforce feelings of being excluded. It is important to support them in this regard.
Therefore, ensure they connect with others living with ADOA, for example through peer support groups. This helps to break through feelings of loneliness and of being different. Also be mindful of risky behavior: young adults are more susceptible to using substances such as alcohol or drugs. This can become a way of coping with difficult situations.

Some substances can exacerbate physical symptoms. You should therefore be open when discussing substance use. Motivational interviewing can help with this.

Be alert to mental health issues that may arise during adolescence or early adulthood. An understanding of conditions such as Charles Bonnet syndrome will help you to avoid confusing visual hallucinations with psychotic symptoms.

This generation is often critical and well-informed. A concept such as ableism (assuming that a life without disabilities is the norm) can be an eye-opener for them. Help them to channel frustration, incomprehension and disappointment into action and awareness.

Support their search for a new vision of the future, and help them to regain a sense of control over their lives despite the changes.

ADOA and adult clients

Adults affected by ADOA often experience a profound loss of independence and identity, particularly when their ability to work changes. At this stage of life, work is closely linked to self-image and a sense of purpose. The loss of a career or the need to retrain requires a grieving process and reorientation. In therapy, it is important to create space for the development of a new self-image, in which pride and strength can take center stage.
In addition, the dynamics within partner relationships change. Increased dependence can cause existing roles to shift, which creates tension and uncertainty. It is essential that both partners learn to discuss this openly with one another under your guidance. Encourage clients to communicate with their social network so that they can expand their support network.

Many clients struggle to find suitable aids or support at work. Actively refer them to local or national support options, organizations and services that can help them regain their independence.
Please note: ADOA is rarely the only issue in your client's life. Raising children and caring for parents (who may also have ADOA) or other responsibilities can be just as stressful. Concerns about fulfilling a desire

to have children or the impact on children already born can be significant. Allow space for the whole person.

ADOA in later life (aged 55 and over)

Sometimes ADOA manifests later in life and may be accompanied by the loss of future plans and independence. This group is often nearing the end of their career and transitioning into retirement. The loss of vision can lead to feelings of gloom or futility, especially if the life they have built up previously suddenly no longer seems achievable.

Advise clients not to make any major decisions in the first year following diagnosis. Building resilience is more important than making changes at this stage. Support clients in finding new sources of meaning, such as volunteering or mentoring.

Regular social interaction and continuing to get out and about are protective factors against feelings of gloom. Be mindful of the digital divide: some older people have fewer digital skills. Guide them through this gently or organize support.
Older clients often have a wider range of coping strategies at their disposal. Help them to become aware of these skills so that they can use them to tackle new challenges.

Parent of a child with ADOA

For parents of a child with ADOA, coming to terms with the loss of sight is an emotionally charged process. Feelings of guilt are common, even though parents know rationally that they could not have prevented this.

The future they had envisaged for their child needs to be re-evaluated. This requires attention to and recognition of 'living loss' – a grief that keeps returning and can never be fully resolved. Try to find a positive outlook together.
Because ADOA often develops in childhood or early adolescence, parents can feel very alone. There are few similar families in their local area. Support from peers or a therapist who is a good listener can help them feel less isolated.
Focus the therapy on the parent's own resilience as well. Parenting on an empty tank doesn't work. Self-care is essential, even though it often feels unnatural to them. Help parents tap into their strength and creativity in their role as carers. Drawing up or refining a good support plan provides practical guidance and increases the sense of control. Offer support in contacting local or national support options, organizations and services for assistive devices, mobility support and guidance from a community support worker.

Parents who have passed on ADOA, or fear they may have done so, often experience intense feelings of guilt. The idea of being responsible for their child's suffering can be paralyzing. Do not immediately dismiss this feeling, but acknowledge it and offer space to bear it together.
In addition, parents may feel overwhelmed. They fulfil many roles at once and have little scope to reflect on their own needs. Therapy can provide a safe space in which they can allow themselves to feel their grief, anger and fear.

A further problem is that ADOA is often not visible to the outside world. This makes it harder to find support. In therapy, emphasize their right to have their experience recognized, even if nobody 'sees' their child's

disability. Provide parents with tools to explain to those around them what ADOA is and what its consequences are. Existing psycho-education programmes, provided by local or national support organizations can be used for this purpose.
Many parents also live with the fear of being (further) affected themselves, which can have consequences for their role as parents. Support them in making healthy choices and coping with uncertainty.

Parent of a young adult with ADOA

If an adult child needs care again due to ADOA, this can feel like a step back in time for parents. The grief associated with this is not only the loss of the child's autonomy, but also of the vision of the future that they, as parents, had envisaged.
Support parents in letting go of control and accepting that their adult child makes their own choices – even if those choices are difficult to watch.
Discuss feelings of guilt, concerns about the future and the balance between providing care and letting go.
Encourage self-care, particularly for older parents who no longer have the energy they once did. Where necessary, refer them to support services and help them connect with other parents in similar situations.

Partner of someone with ADOA

Partners of people with ADOA often put their own needs aside. They focus on the other person first. By the time they seek therapy, a great deal has often already happened. As a therapist, it is important to acknowledge that ADOA affects them too. Their emotions are valid.

Partners sometimes feel guilty about their own grief, or wonder whether they are allowed to express it. Allow space for that grieving process.
Many partners take on additional roles, such as driver, organizer or caregiver. This shift can cause tension in the relationship.
A recurring theme is fear: the fear of leaving the other person alone, or of no longer being there themselves. In practice, this often means that partners have less time for themselves. Help them to set and maintain their boundaries and find ways to look after themselves properly too.

Some partners feel overwhelmed or insecure. Acknowledge their efforts and offer guidance on finding a balance between caring for their partner and looking after themselves. Consider arranging online sessions if that is more practical, especially in the early stages.

Adult child of someone with ADOA

For an adult child of a parent with ADOA, it is painful to see the familiar parental role shift. The parent is no longer the main source of support; sometimes the child takes on that role. This can lead to sadness, confusion, feeling overwhelmed and an increased sense of responsibility. At first, these clients often say little about themselves, as they are used to putting others first. Give them space and time to build trust. You can then guide them in exploring their own feelings, fears and needs.

Common concerns include: “Can I continue to live my life as planned?” or “What if my parent is no longer here?” Questions about inheritance and starting a family may also come into play.

Support them in finding a new balance in their relationship with their parent and help them to normalize emotions such as guilt, sadness and even frustration. Self-care and autonomy deserve particular attention during the sessions.

Siblings of someone with ADOA

Siblings of people with ADOA are often overlooked. Attention within the family usually focuses on the sibling with ADOA. Yet they are going through their own process, often in silence. They sometimes feel obliged to be ‘strong’, which comes at the expense of their own emotional space. As a therapist, acknowledge their position. Make it clear that their feelings certainly matter too. Issues such as jealousy, guilt (“why them and not me?”), and excessive responsibility are normal. Help them to identify these underlying emotions. Some brothers and sisters become accustomed to a caregiving role. This can have an impact later in life. Work on setting boundaries, assertive communication and their right to follow their own path as well.

Family planning with ADOA

People who carry an ADOA mutation – whether they are already visually impaired or not (yet) – are confronted with the impact of this genetic condition. ADOA is inherited in an autosomal dominant pattern, which means that all parents, regardless of gender, can pass it on to their children.

As a therapist, it is important to approach the topic of family planning with care. For many people, the fear of having a child with ADOA plays a major role. This can lead to anticipatory grief: sadness over a possible future that has not yet arrived. Rarely do those in the social environment or healthcare professionals ask about this very real fear, even though it plays a significant role in the lives of expectant parents, one of whom carries the ADOA gene.
Many people who carry ADOA also feel a deep sense of empathy for others. Whilst this is a strength, it can also be a burden. Their focus on the needs of others is sometimes so intense that they struggle to articulate their own feelings and wishes, or to prioritize their own wellbeing.

As a therapist, you can help by gently redirecting that focus back to the person themselves. Strengthening self-awareness and self-care contributes to a better emotional balance. Consider the well-known example of the oxygen mask on a plane: you must first take proper care of yourself before you can be there for someone else.
A referral to a clinical geneticist and/or a gynaecologist may be necessary if parents express a wish to be informed about matters such as IVF with embryo selection.

More than just visual impairment – ADOA-plus

Some people with ADOA experience not only visual impairments but also what is known as ADOA-plus. This form of the condition is accompanied by additional symptoms that can affect the nervous system, hearing and muscles.

Possible symptoms include: hearing loss, muscle weakness, balance problems (ataxia), coordination difficulties, numbness, muscle cramps, migraines, fatigue, tremors, heart problems (cardiomyopathy), and sometimes also diabetes or stiffness in the legs (spastic paraparesis). These symptoms can be severe and often only become apparent in adulthood, precisely at a stage when responsibilities at work and in private life are increasing.

In therapy, it is important to support people with ADOA-plus in reshaping their daily lives. This includes practical solutions, such as energy management, and incorporating moments of rest. Emotional processing also deserves attention: the loss of physical control can lead to anger or frustration. Assistance with referral to a center of expertise for mitochondrial diseases may be necessary and helpful.

Exploring existing strengths and resilience helps clients to continue to feel in control despite their limitations. Life changes, but with appropriate adjustments it can still be valuable and meaningful.

As symptoms can vary from day to day, flexibility in treatment is crucial. Offer video consultations where necessary and be understanding if sessions need to be rescheduled or cancelled.

Note: ADOA is already rare; ADOA-plus is even less common. Referring clients to peer support groups or specialist information sources can help them feel less isolated.

About the Cure ADOA Foundation
Since November 2018, the Cure ADOA Foundation has been working to support people with ADOA(-plus) and their families.
Website: www.adoa.eu/en
Email: info@adoa.eu

CURE ADOA FOUNDATION