Psychosocial Interventions in Motor Neurone Disease

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“Dying is not just a physical experience.

Bereavement is not just an emotional experience”
We split the human body up into its separate components, but this does not exist in reality – we are an integrated whole. You cannot affect one part without influencing the others............the same is true of a family........

“If one part suffers, every part suffers with it; if one part is honoured, every part rejoices with it.”

1 Corinthians 12:26 (NIV Bible)
“The Tale of Roselle” – Hamburg July 1943
“The Seven Pains”

Physical / practical
Emotional / psychological
Social
Spiritual
Religious
Mental
Financial
Remember, those pains can be experienced by the carer(s) and family as well as the patient.
INITIAL PSYCHOSOCIAL ASSESSMENT

Physical / Practical: illness / treatments / abilities & disabilities / independence / care responsibilities & impact / communication & transportation / care workload / food / warmth / aids and adaptations (IT) / broken equipment / food bank / Maslow Other

Emotional / Psychological: personality / mental health history / HAD / coping strategies / losses & grieving / developmental milestones / historical antecedents e.g. abuse, war, domestic violence, bullying – school, work or home / addictions / suicide risk / trauma / drugs / alcohol / Emotional Needs Audit

Social / Support Networks: family, friends, colleagues – utilised, potential, non-existent / telephone, internet, visitors / social contact – availability, opportunity, realistic perception / housing – location, type – isolation issues / attitudes of care givers / Other

Mental: intellectual stimulation / creativity / work satisfaction / hobbies & interests / leisure activity – physical, sports / practical & physical barriers to mental fulfilment / Other

Financial / Housing: debts / benefits / grants / housing or equipment repairs / heating / clothing / cash flow crisis / overcrowding / wrong type or location of accommodation / repossession / insurance issues – general / Other

Spiritual: meaning – people, things, activities / values / fears / guilt / forgiveness / reconciliation / unfinished business / hope(s) / view or perception of current situation – fate, God etc. / Other

Religion: faith / beliefs / rituals / current view of God or creator / practicing / issues of punishment & judgement / doubts / altered beliefs / comfort and strength / source of distress / Other

Legal: children / divorce and separation / marriage or partnership / wills / criminal proceedings (self or others) / mitigation / witness / benefits / housing / debts / insurance – conflict / issues requiring advice or intervention by solicitor / mental capacity / LPA / Advance decisions / Other

Child Protection: identification / concerns / risks / evidence / notification

Safeguarding Adults: responsibility / Other

Issues of Culture / Ethnicity: (give details)
Physical / Practical:

1. illness - diagnosis, impact (possibly of carer too)
2. treatments - effect, time, frequency, useful or destructive
3. abilities & disabilities - capability
4. independence / carer responsibilities & impact
5. communication & transportation
6. carer workload
7. food / food bank
8. warmth - heating, clothing - cost
9. aids and adaptations (medical physics, OT)
10. broken equipment – washing machine, fire
11. Maslow hierarchy – basics need to be met first
12. Other…………………………
Emotional / Psychological

1. Personality difficulties
2. Mental health history
3. What are the coping strategies being used
4. What previous losses have occurred and how dealt with including losses through never having
5. What developmental milestones are current
6. Historical antecedents such as trauma – war, abuse, domestic violence, bullying
7. Addictions – drugs, alcohol
8. Risk of suicide
9. Emotional Needs Audit – Human Givens Institute
The Emotional Needs Audit

How well are your innate emotional needs being met?

Nature has programmed all of us with physical and emotional needs. These are the 'human given' that cannot be avoided. How stressed we are depends on how well they are being met now, and how well we deal with the situation when they are not. Rate, in your judgement, how well the following emotional needs are being met in your life now, on a scale of one to seven (where 1 means not met at all, and 7 means being very well met), by ticking the appropriate boxes.

- Do you feel secure in all major areas of your life (such as your home, work, environment)?
- Do you feel you receive enough attention?
- Do you think you give other people enough attention?
- Do you feel in control of your life most of the time?
- Do you feel part of the wider community?
- Can you obtain privacy when you need to?
- Do you have an intimate relationship in your life (one where you are totally physically and emotionally accepted for who you are by at least one person, this could be a close friend)?
- Do you feel an emotional connection to others?
- Do you feel you have status that is acknowledged?
- Are you achieving things and competent in at least one major area of your life?
- Are you mentally and/or physically stretched in ways which give you a sense of meaning and purpose?

- If your scores are mostly low, you are more likely to be suffering stress symptoms.
- If any need is scored 3 or less this is likely to be a major stressor for you.
- Even if only one need is marked very low it can be enough of a problem to seriously effect your mental and emotional stability.

Stress, anxiety, anger, depression and addiction are the result of our innate needs not being met, either due to environmental factors, harmful conditioning or a misuse of imagination (worrying). People do not have mental health problems when their innate needs are being met in balanced, healthy ways. By highlighting areas in your life where your essential needs aren't being met as well as they could be, you can use this questionnaire to help you think constructively about how your life could be improved.
Social / Support Networks

1. Make up of family – supportive elements

2. Friends – supportive? ‘Takers or givers’

3. Work colleagues – supportive employer and work force?

4. Are support networks recognised and utilised, are they potential / non-existent, realistic perception (e.g. say no one comes, yet have a stream of visitors!)

5. Access to telephone, internet / Skype, (Mobile phone / computer)

6. Social contact – availability, opportunity

7. Housing – location, type, overcrowding – isolation issues

8. Attitudes of care givers
Mental Needs

1. Practical and physical barriers to mental fulfilment
2. Intelligent – good mind in a body that doesn’t work anymore
3. Level of stimulation – can it be increased
4. Ability to engage in creative activities
5. Work satisfaction
6. Hobbies and interests – can they be supported
7. Engagement in leisure activities – sport, games, walking
8. BASICPh
BASIC PH – coping and resiliency

B – Beliefs
A – Affect / emotions
S – Social / relationships
I – Imagination and creativity
C – Cognitive / intellectual
Ph – Physical exercise

To be able to function we need at least two of these coping strategies to be operative in our lives. This has major implications for patients especially, but also families and bereaved. Just spending time with someone and encouraging the sharing of emotions, raises the coping strategies by one.

Prof. Mooli Lahad and Dr. Ofra Ayalon
Financial / Housing

1. Debts – now includes funeral debt which has become a massive problem
2. Benefits Issues – a very big issue now
3. Housing or equipment repairs
4. Heating costs rising
5. Clothing needs changing
6. Cash flow crisis – can lead to Food Bank
7. Grants available
8. Wrong type or location of accommodation
9. Repossession
10. Insurance issues – life policy, flood damage etc
1. What brings meaning to people’s lives – people, things, activities
2. Their values – needs respect
3. Fears – terminal agitation? Difficult pain and symptom control
4. Guilt
5. To forgive / need to be forgiven
6. Reconciliation
7. Unfinished business
8. Hope (s)
9. View or perception of current situation – positive or negative
10. Fate or faith
Religious

1. Many people do not follow any particular religion, but believe deeply about ‘something’ – life after death, God. Don’t ignore – may need acknowledgment

2. What are their beliefs – find out, ask, don’t assume

3. What rituals are important – ask

4. Practicing or non-practicing (why?)

5. Current view of God or creator - Issues of punishment, judgement – hope, love (SAS)

6. Need for forgiveness, need to find peace (with God)

7. Doubts, altered beliefs - faith challenged – finding faith

8. A source of comfort and strength, or of distress and disturbance (SAS)

9. Need for involvement of priest or other religious figurehead
Legal Issues

1. Future of children
2. Divorce and separation
3. Marriage or partnership – heterosexual or gay
4. Wills!!
5. Criminal proceedings (self or significant others) – mitigation, witness
6. Benefits (and appeals)
7. Industrial tribunals
8. Debts and repossession
9. Insurance issues
10. Mental Capacity Act (Best interests and DoLS)
11. Lasting Power of Attorney
12. Advance decisions / withdrawal of treatment (removal of the mask)
Patient & Family

Families Together

Consultant Neurologist

Physiotherapy

GP

Hospice Medical Team
Inpatient Unit
Day Unit

Hospice Social Worker

Social Services
Adults / children

Complementary Therapy

Music therapy

Medical Physics

MND Specialist Nurse

Carers / Care Agency

Community Nurse

Other specialisms – NIV etc

Welfare Rights / CAB

Occupational Therapy

Chaplain

Home from Hospital
What does this teach us?

The invasion of people’s lives (and homes) – try to limit it

Need for joint working

Need for a functioning MDT

No one has all the answers

Respect for what other disciplines can bring to the table

No place for professional jealousy or possessiveness

Need for good communication - paramount
Systems Theory

A change in one part of the system, involves changes in the other parts of the system:

The Role of Communication

The need for good communication with the patient
The need for good communication between professionals
The patient cannot be seen in isolation from the 'system'
What Hinders Us from Good Communication

Fear of what we will dig up – overwhelmed
Don’t know where to turn
Fear of being seen to be incompetent
Facing our own mortality
Fear of MND itself
Being judgemental – poor attitude
Compassion fatigue
Arrogance – I can do it alone
Overworked
A Few Things to Think About

Don’t make assumptions – esp. relationships. Partners love each other, gay relationships, that all pain has a physical cause.

Don’t be shocked by difficult behaviours – why do you expect them to be grateful or behave well – they are dying or watching their loved one die! They may have been abused, mental illness, personality disorder, hopeless, despair, suspicious, frightened, fight /flight reactions – acting out of character

Mental Capacity Act – allowed to make ‘unwise’ decision – not to be paternalistic, least restrictive decision making for those lacking capacity – don’t misconstrue inability to communicate verbally for lack of capacity - wishes and feelings (A and the mask)
Denial is a coping strategy – absolute vs quality of life, how to deal with it, can’t force the door open – you do so at great risk to them – what happens if you do.....Tammy – not wanting to leave children.

Problems it raises for family. Need for trying to obtain LPA, advance decisions, voice banking – can’t do these things where there is denial. Careful with PPOC and DNacPR questions.

Don’t make judgements - about family and their involvement or lack of it – you don’t know the history. Family dynamics
Depression can be a coping strategy – a block – the ‘face to the wall’ – I want to die – dysfunction, negativity, can’t adjust or reframe - leaves family cut off and isolated. Have you thought about what is causing the anxiety or depression? No point just using tests and scales. Think of the Emotional Needs Audit mentioned earlier.

Why is the patient or family member anxious or depressed? Can it be treated by other than medication? – investigate the cause of the problem........

Worried about bills, relationships, those they leave behind?
You need to be a sports person to keep up with the changing goalposts of the patient and the progressing illness!! - MND feels like it is in control – changes what you can do and what you can talk about. You can plan adaptations, but may be useless by the time they arrive – try to look ahead – be ‘on the ball’ - and take the patient with you if they will allow – be brave, but sensitive

Consider all the losses – progressive, unrelenting, sudden, current developmental milestones, losses through never having – issues around never having grieved
Be aware of safeguarding concerns – what preventative work can you do? Remember, a patient may suffer abuse and put up with it for reasons that are hard for you to understand / remember MCA and capacity.

Don’t avoid raising safeguarding concerns – you do it, take responsibility.

MND is palliative from the point of diagnosis – it’s a ticking time bomb and time is running out. You need to be onto psychosocial issues as soon as possible as the time will run out and you can’t achieve what is needed even in a patient family situation that is open.

Early psychosocial intervention is crucial.
Be prepared for the lid to come off – past trauma, abuse, violence, childhood neglect, suspicion, non-compliance, war, relationship problems, conflicting families, financial jousting, personality disorders.

Be prepared for being manipulated, set boundaries. MND is a terrible disease and can tap into our deep concern for people, pushing us to go over the top, take risks, create dependence.

How will you cope with a patient who wants to remove their mask? Support or abandonment.

The clash of illness and bereavement – the energy required to grieve when ill. For MND patients husband, miscarriage, children die.
Recognising what is important to the patient and making it happen – the horse!

Finance – PIP appeals, Universal Credit, being found fit for work. Patients and carers need advocates to fight the injustice of the current system.

We may be the only experience of love and kindness the patient / carer has ever experienced – and it may be too painful for them to bare.

Look after you! It’s tough!!
Fears or Concerns of the Dying Patient and Their Carer/Family

Where will I die? / Where will they die?

When will I die? / Do I prepare for their death? Guilt

How will I die? / What will I witness as they die? Can I cope?

What about my loved ones? / What about us? The future without them?

Who will remember me? / Will I forget them? Fear of betrayal
Cont’d …..

What have I achieved? / I wish we had

I have regrets / I have regrets

I need to be forgiven / Will they be at peace? Tormented, agitated?

I need to forgive / Will they forgive me before they die?

I have unfinished business / Will we get things sorted out?

What happens when you die – God, hell? / Will I see them again?
Will I meet those I hurt on the other side? / I have fears for them after death?

Will I die alone? / Will I be there?

Will my carers abandon me? / Can I finish this to the end?

I am a burden / the burden may become too heavy

There is nothing left to live for / Will they give up? Are we worth fighting for? Do we still matter?

How will I be remembered? / A bad relationship? Memories that are not good. Loss from never having
THANK YOU!