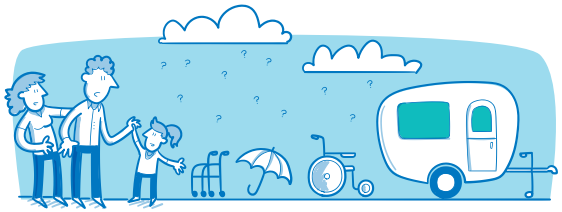
ALS
CONVERSATION CARD



ALS will affect your life

ALS, PMA or PLS has a major impact on your life. Your rehabilitation doctor will help you choose appropriate care and aids, suited to your wishes and needs. Together, we strive to achieve the best possible quality of life.

Why use this card?

This conversation card helps you discuss what is on your mind, what is going well and what can be improved. It reminds you of important issues, helping you to ask the right questions.

Choose a topic to discuss with your doctor

1

My disease

2

My body

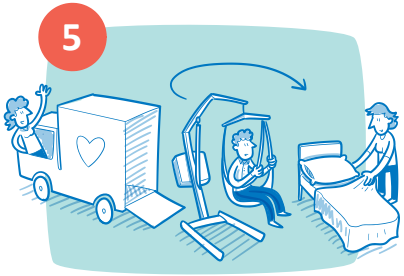
3

My daily life and activities

4

Coping with my disease and its consequences

5



Getting things organised

6

My partner and family

7

My thoughts and emotions

8

My social life

9

My treatment

10

My end of life

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Select 3 topics you would definitely like to discuss. Missing a topic? Please, add it in the text box market with: ?

Bring the completed conversation card to the appointment with your doctor.

1 My disease:

- ☐ Diagnosis
- ☐ Expectations about how my disease will affect me
- ☐ Heredity
- ☐ Other diseases that I have in relation to ALS, PMA or PLS
- ☐ (New) treatments

2 My body

- ☐ Involuntary muscle movements (spasms and cramps or muscle twitches)
- ☐ Muscle weakness
- ☐ Stiff joints
- ☐ Cold arms, hands, legs or feet
- ☐ Fatigue and low energy
- ☐ Pain
- ☐ Wounds and/or bedsores caused by lying or sitting
- ☐ Swallowing
- ☐ Saliva/mucus
- ☐ Breathing
- ☐ Changing the way you sit/lie down
- ☐ Influence of menopause/hormones
- ☐ Weight
- ☐ Changes to my body

3 My daily life and activities

- ☐ Sleep
- ☐ Eating and/or drinking
- ☐ Pooping and/or peeing and wiping yourself
- ☐ Washing and/or getting dressed and undressed
- ☐ Speech and being understood (intelligibility)
- ☐ Writing and/or typing
- ☐ Reading
- ☐ Standing, sitting and/or lying down
- ☐ Sport and/or exercise
- ☐ Walking and/or moving around indoors and outdoors
- ☐ Getting around in traffic and/or driving
- ☐ Household tasks
- ☐ Following education/courses
- ☐ Work and/or voluntary work; stopping or continuing work
- ☐ Holidays
- ☐ Hobbies and/or leisure time
- ☐ Providing and/or receiving informal care

4 Coping with my disease and its consequences

- ☐ Autonomy and/or self-management
- ☐ Loss of dependence and reduced participation
- ☐ Asking for and accepting help
- ☐ Meaning in life and religion
- ☐ Loss and grief
- ☐ (Coping with) homecare

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5 Getting things organised

- ☐ Assistive devices and equipment
- ☐ Home modifications
- ☐ (Health) Care
- ☐ Money and insurance
- ☐ Care regulations and reimbursements:
  - ☐ Social Support Act – in Dutch: Wet Maatschappelijke Ondersteuning (WMO)
  - ☐ Personal Budget – in Dutch: Persoons Gebonden Budget (PGB)
  - ☐ Health Insurance
  - ☐ Long-Term Care Act – in Dutch: Wet Langdurige Zorg (WLZ)
- ☐ Mobility
- ☐ Moving home and care homes

6 My partner and family

- ☐ Coping with the disease and its impact on partner and family
- ☐ Talking about your disease with your partner and family
- ☐ Changes in partner role and/or parenting role
- ☐ Affection/ Intimacy/ Sexuality
- ☐ Care for partner and/or children
- ☐ Resilience and burden of partner and/or children
- ☐ Impact of changes in thinking and/or behaviour on your loved ones
- ☐ Follow-up care for partner and/or children

7 My thoughts and emotions

- ☐ My future
- ☐ Living with uncertainty
- ☐ Feeling afraid, sad or depressed
- ☐ Coping with my disease
- ☐ Feelings of guilt
- ☐ Being angry
- ☐ Feeling stressed
- ☐ Shame
- ☐ Feeling lonely
- ☐ Thinking about death
- ☐ My behaviour has changed (according to others)
- ☐ Changes in memory, thinking and understanding
- ☐ Uncontrollable crying and laughing

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8 My social life

- ☐ Informing family members and others about the disease and expected changes
- ☐ Relationship with family, friends, colleagues etc.
- ☐ Help from family and/or social network
- ☐ Support and understanding
- ☐ Social exclusion
- ☐ Peer support

9 My treatment

- ☐ Medication
- ☐ Side effects
- ☐ Tube feeding
- ☐ Urinary catheter
- ☐ Ventilation (breathing support)
- ☐ Care and treatment preferences

10 My end of Life

- ☐ How much intervention am I willing to accept (feeding tube, ventilator, Intensive Care)
- ☐ End of life:
  - ☐ Relieving pain and distress with medication (palliative sedation)
  - ☐ Euthanasia
- ☐ Letting go of life and/or loved ones
- ☐ Will and Testament (solicitor)
- ☐ Advance decision and consent (General Practitioner)
- ☐ Power of attorney (e.g. financial)
- ☐ Organ donation and/or codicil
- ☐ Going to a hospice
- ☐ Burial or cremation

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