# I want to know...

# What does my diagnosis mean and what can I expect?

What is my outlook for the future, as you see it?

How was the diagnosis made?

Might my diagnosis change?

How advanced is my illness?

What are the symptoms I am likely to experience, both now and as my illness progresses?

What kind of changes will I have to make in my work, family life, sex life, and leisure time?

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| Where will I be cared for?  |
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| Who will be part of my healthcare team?<br>Will there be different people involved? |
| Will I need any equipment in my home as my condition progresses?                    |
| What support is available to help me and my family?                                 |
| Who should I contact if things get worse?   |
| Can my family members be involved in decisions?                                     |

# How long have I got?

How long am I likely to live for?

Am I likely to die from this illness?

#### What will happen when I am dying?

What will happen to me at the very end?

How will I actually die?

Will I be conscious at the end?

Will I be in pain?

# My priority is...

# To live as long as possible

What treatments will enable me to live as long as possible?

Can you slow down the progression of my illness?

# To have a good quality of life

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Would your recommendation change if I told you that my priority is having a good quality of life, so, living as normally as possible for as long as possible?

How will this illness affect my quality of life?

I like to \_\_\_\_

how can I ensure I get to do these things for as long as possible?

What are the best things I can do to stay as healthy as possible?

I do not want to swap a bad situation for something worse. Could this treatment make me feel worse than my illness already makes me feel?

# Treatment decisions

# What are my treatment options?

| What are my treatment options? Can you explain the benefits and things I should consider for each one?         |
|--|
| Are there other ways to treat my illness?  |
| Do I need more than one sort of treatment?   |
| Is my decision urgent or can I take more time to think about it? What will happen if the treatment is delayed? |
| What will the treatment be like? How long will it take?  |
| If the treatment you are suggesting does not work,<br>or the side effects are bad, what are the other options? |
| Where will I have this treatment? Will it be in hospital?<br>How long will I be in there?                      |

# What will this treatment do?

| What is the aim of this treatment? Will it cure the illness<br>or will it just help my symptoms or slow the illness down? |
|---|
| Are there any risks with this treatment?  |
| Is there any chance that this treatment will make me worse?   |
| How will I know if the treatment is working?  |
| How many people in my situation benefit from this treatment?  |

# Are there side effects?

Are there any side effects? If there are side effects what are they like, and can anything be done about them?

If I find the side effects unacceptable can I stop the treatment?

#### Not having treatment

What will happen if I choose not to have treatment?

What is the natural course of my illness if left untreated?

#### After treatment

How will I feel after the treatment?

How long will it take after treatment to recover?

What will my life be like during and after the treatment?

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will I be able to do these things after this treatment?

# Having tests

What will the results of this test tell me?

How will the result affect your recommendation for my treatment?

How will this test help me make a decision about treatment?

# My religion and spiritual beliefs

How can I access spiritual support?

How can I be supported to ensure any rituals important to me are honoured?

How can I be referred to a representative of my faith or a Chaplain?

# Things to find out about

| $\square$ | Where can I get counselling?  |
|-----------|---|
|           | Are there any support groups for me and/or my carer?  |
|           | What benefits am I entitled to?   |
|           | What support is available at home, for example nursing, help with washing and dressing, and help with shopping? |
|           | Will I need practical living aids and equipment, and how can I arrange this?                                    |
|           | Who can I call if I am worried or my health changes?  |
|           | l live on my own, so do I need a personal alarm to alert<br>people if I fall or am in trouble?                  |
|           | Am I entitled to a disabled badge?  |
|           |   |