

**We suggest you highlight or underline the questions you want to ask and take this sheet with you to the hospital. The consultant or the specialist cancer nurse will do their best to answer all your questions. You might wish to write down some of the answers so take a pen or pencil with you.**

### ***General***

Will you be honest in answering my questions?

Will you use language I can understand?

### ***Asking about GIST***

Why has this happened to me?

What is GIST?

What causes sarcomas like GIST?

Could it have been caused by (radio mast/chemicals/sports injury)?

Have I brought this on myself – smoking, wrong eating etc?

Have I inherited it?

Could I have prevented it?

How long have I had it?

Why wasn't it detected earlier?

What are my chances of making a full recovery?

Will my children get sarcoma or GIST too?

How many people get this disease?

### ***What will happen to me ?***

Will I die?

Is there a cure?

What treatment will I receive?

Is there any alternative ?

### ***Telling others***

How do I tell ... partner/children/parents/employer/colleagues?

Is there a support service for sarcoma patients at this hospital?

Who can help me claim benefits?

How will I get to and from hospital?

How can my GP support me?

### ***Understanding the tests***

Do I have to have all these tests?

What is a CT scan?

What does it show?

What is an MRI scan?

What does it show?

Why do I need a biopsy?

### ***Discussing initial treatment***

What are the side effects of treatment?

Are there any ongoing side effects?

What if the treatment doesn't work?

Will my treatment be as an in patient or out patient?

How long will I be in hospital?

How will my life be affected during treatment?

What are the chances of it returning again after I recover?

Will I be able to lead a normal life after treatment?

What must I avoid doing and what can I do?

Are there any new drugs which can help me?

What is remission?

### ***Discussing surgery***

Will this treatment cure me?

What will the operation involve?

Have you done a lot of these operations before?

What are the risks with this surgery?

How long will it take?

How long will I be in hospital?

How long before I can get out of bed after the operation?

Will I be disabled as a result of surgery?

How will you help me recover back to a normal life?

What follow up treatment will be needed?

What other long-term side effects will I have?

## ***Understanding Glivec***

Will this treatment cure me?

How long do I have to take it?

How do I take it?

Are there any day-to-day drugs (like aspirin) I must not take with it?

What are the side effects?

How will you treat the side effects?

How long does it work for?

What if tests show it isn't working?

Are there any long-term side effects?

## ***Follow-up and monitoring***

What follow-up monitoring are you proposing?

Do I have to come to you for every follow-up clinic or can my GP help?

When can I return to work?

Can I eat what I like?

Do I have to take any special precautions?

Can I go on holiday?

Can I fly abroad on holiday?

Can I continue to drink (or smoke)?

Can I use complementary medicine to help me?