

Compliance with treatment



***Be an active partner
in your GIST care
every day***

Introduction

The emergence of targeted therapies in the treatment of certain cancers, including GIST, is a milestone in the progress of oncology.

The development of these new drugs, which are pills people take home and manage themselves, has significantly changed the way of treating these cancers. This progress not only allows patients to have a better quality of social and family life by reducing the time spent in hospital, but also grants them a level of responsibility for managing their treatment and ensuring its potential effectiveness.

Using these new therapies brings GIST patients to face a new form of treatment autonomy they never had before.

Now, they have to learn to manage it on a daily basis, away from the hospital and healthcare teams.

Compliance at home is now a challenge to take up...

What about you?

How are you dealing with your treatment?

Have you ever:

- ***Forgotten to take your pills ?***
 Yes, rarely Yes, sometimes Yes, often No, never
- ***Stopped taking them for a short time without asking your oncologist ?***
 Yes, rarely Yes, sometimes Yes, often No, never
- ***Delayed or postponed taking them for more than 12 hours?***
 Yes, rarely Yes, sometimes Yes, often No, never
- ***Combined them with other drugs without checking with your oncologist, or without prior communication with him ?***
 Yes, rarely Yes, sometimes Yes, often No, never
- ***Deliberately changed the dose without asking your oncologist ?***
 Yes, rarely Yes, sometimes Yes, often No, never
- ***Forgotten to go to the pharmacy to get your pills ?***
 Yes, rarely Yes, sometimes Yes, often No, never
- ***Needed someone to remind you about taking your pills ?***
 Yes, rarely Yes, sometimes Yes, often No, never
- ***Ignored some medical recommendations about your treatment?***
 Yes, rarely Yes, sometimes Yes, often No, never

If you answered

“Yes”

**to one or more
of these questions**

then . . .

**you may have
compliance
problems**

What is “compliance”?

“Compliance” describes the way in which a patient takes a prescribed medication, following the instructions of his or her oncologist, with regard to :

- ***Taking the correct dose.***
- ***Taking the pills at the correct time.***
- ***Taking them in the best way.***
- ***Being careful not to eat foods or take other medicines which might interact adversely with the cancer drug.***

Compliance plays a vital role in the fight against the disease and enables people to take control of their treatment and to play a full part in their care.

A GIST diagnosis is always potentially life-threatening, that’s why good compliance is essential if patients are to have the best possible chance of long-term survival.

And yet...

Did you know?.....

**On average,
a patient treated
with imatinib**

“misses”

**109 days of treatment
a year**

or nearly

**1/3 of their
annual dose**

and,

this

**significantly
increases**

the risk of relapse

Factors which can adversely affect compliance

Several factors may contribute to poor compliance :

- *Psychological disorders, dependence upon, or addiction to alcohol, drugs and anti-depressants.*
- *Financial, social, family or professional problems.*
- *A complicated treatment pattern.*
- *Relationship problems with the healthcare team.*
- *Frequency of appointments, distance from the hospital, or poor medical supervision.*
- *Mental or physical handicaps, psychiatric illness.*

Most problems with compliance can be explained by a lack of information about :

GIST

GIST patients must understand and accept that they have a serious **chronic disease**, a very rare cancer of the digestive system which involves a high risk of mortality if not treated effectively.

Treatment for GIST

Patients with an advanced and/or inoperable metastatic GIST are now first treated with targeted “anti-cancer” drugs which are less constraining and toxic than conventional chemotherapies.

Although these new treatments may seem very simple, their positive effect on the life-expectancy of these GIST patients is now undisputed. Before oncologists started to use targeted therapies to treat GIST, only 20% of patients with an advanced and/or inoperable metastatic disease treated with conventional chemotherapies survived for more than one year. Since these new drugs are prescribed, more than 90% of them are still alive and well after one year of treatment.

However, the necessary duration of the treatment is now unknown as there is still no drug which can totally eradicate all GIST cells. Therefore, many GIST patients should probably be treated for life or until it is clear that the drugs are no longer being effective.

Side-effects of the treatment

Even if they feel they are just taking pills, GIST patients have to realize that they are being treated for a real cancer with a real and effective treatment. They also have to know that any anti-cancer treatment, even when taken orally, probably produces side-effects.

Poor communication, and the fact that patients are not given this information may be responsible for many cases of poor compliance.

Many patients do not know that most side effects tend to subside, or even disappear with time, and that their oncologist can help them to manage these side-effects without compromising the effectiveness of the drugs.

Without the necessary information and support, a patient who is suffering badly from side-effects and is feeling unable to cope with them, may try to reduce them by :

- **Lowering the dose.**
- **Interrupting the treatment for a few days.**
- **Self-medicating with other drugs.**
- **Stopping the treatment.**

Any of these can have serious consequences for the patient, and may jeopardize his chances of survival, as these practices certainly reduce the effectiveness of the treatment.

What you need to know...

Although patients using these new treatments may look and feel very well, GIST remains a serious disease, a cancer that must be treated very carefully to give patients the best possible chances of survival.

Poor compliance with the drug treatment can have serious consequences :

- **Decreased effectiveness of the treatment.**
- **Development of resistance mechanisms.**
- **Appearance of other symptoms or diseases caused by drug interactions or treatment discontinuations.**
- **Progression of the disease.**
- **Recurrence of the disease.**
- **More time spent in hospital.**
- **Death.**

The emergence of targeted therapies has dramatically changed the way GIST are treated and tremendously improved patients' quality of life.

However, the insignificant "pill aspect" of these new treatments and the fact that patients have to manage them by themselves at home also contribute to reducing the importance of the drugs as well as the seriousness of the disease.

Yet, the fact that drugs are so easy to take does not mean they are not vital for patients...

The risks involved in poor compliance are real and also constitute an important public health problem.



Patients with compliance problems see a doctor three times more often than other patients

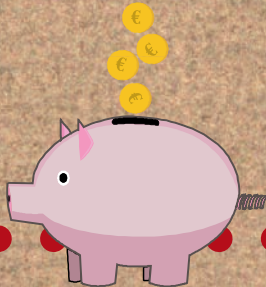
The financial consequences of poor compliance are considerable and contribute each year to the growing financial deficit in our healthcare system.

The decline in the health of some patients caused by not taking the pills regularly, or by self-medication that interferes with it, rapidly leads to :

- **More frequent medical consultations.**
- **Prescriptions of additional drugs.**
- **More examinations and tests.**
- **More time spent in hospital.**

All these increase the costs to the health service and are bad not only for patients but also for the national economy.

Good compliance is not just an individual concern, it is also an important social responsibility.



How to overcome compliance problems

As a patient

Compliance problems can happen to anyone :

- **Remember that you are not alone with your problem. talk to your family and to your oncologist.**
- **Do not modify your dosage yourself.**
- **Do not take any other drugs without checking with your oncologist.**
- **Never stop your treatment without medical advice.**

If you have severe side-effects which you find intolerable or which are seriously affecting your life :

- **Don't wait for your next appointment to tell your oncologist about them.**

He may be able to help you to reduce these effects with other suitable drugs or possibly by reducing your dose if he thinks this is advisable.

Helpful hints and tips

As a family member or caregiver

Compliance with treatment is teamwork, especially when the patient is an elderly person or a child.

- **Listen to the difficulties the patient is having.**
- **Know how the patient is supposed to take his or her pills.**
- **Try to make sure that the dosage is followed correctly.**
- **Remind him or her to take their pills when he or she “forgets” to.**
- **If the patient says he wants to stop the treatment, encourage him to talk to his oncologist about his feelings.**
- **Go with the patient to their appointments to help him to talk about his difficulties.**



Treatment memos... so you don't forget :

- **Use a pillbox.**
- **Use a chart and tick the box.**
- **Organise telephone or text message reminders.**
- **Use an alarm clock.**

To reduce potential problems :

- Take your pills with a meal and a big glass of water to avoid stomach pains.
- Do not drink alcohol during the meal when you take your pills, because the two do not mix well.
- If your pills make you drowsy during the day take them with dinner. If they keep you awake at night, take them with breakfast.
- Do not drink grapefruit juice during the treatment as it seriously decreases the effectiveness of the drugs.
- If you have any doubt about how to take your pills, contact your oncologist.

NON-COMPLIANCE LOG

(Show to your oncologist)

| Date of "missing" | Reason for "missing" (tick as appropriate) | | | | | Notes and explanations |
|-------------------|---|--|--|---------------------------------------|--------------------------------|------------------------|
| | Forgot <input type="checkbox"/> | Rare occurrence <input type="checkbox"/> | Grogginess from treatment <input type="checkbox"/> | Side-effects <input type="checkbox"/> | Other <input type="checkbox"/> | |
| | Forgot <input type="checkbox"/> | Rare occurrence <input type="checkbox"/> | Grogginess from treatment <input type="checkbox"/> | Side-effects <input type="checkbox"/> | Other <input type="checkbox"/> | |
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