

The role of Transplant (TX) in MPNs-patients' Perspective

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→ The most popular patient internet forum for transplant
of adults in German-speaking countries within Europe.

The unexpected happens

Signs of acceleration

Myelofibrosis (MF)

Decision
Decision

D

TX

blast cells
phase



Why transplant at all?

- ◆ **NO** other curative therapy is available.
- ◆ Quality of life decreases as myelofibrosis progresses.
- ◆ Myelofibrosis could enter blast cell phase or (also) transform into Acute Myelogenous Leukaemia (AML). Both of which significantly worsen the prognosis for transplant.
- ◆ Even if you can survive for a while with the help of transfusions and/or drugs, **death** is inevitable in final phase of MF.

Risks vs. chances

- ◆ **Risks:** Graft versus host disease (GvHD) - from mild to moderate to severe and even life-threatening; relapse of myelofibrosis → possibly further transplant(s) or death; late side effects - cancers and other quality of life limiting effects
- ◆ **Chance:** To get rid of myelofibrosis with its associated symptoms once and for all and hopefully for good and to no longer suffer from it

How to deal with panic before TX?

- ◆ The doctor said to me: "You should be more afraid of the disease than of the therapy!"
- ◆ Further development of transplant technology → The possibilities for the patients have been improved considerably.
- ◆ Information is better than speculation! Information and advice prevent panic!
- ◆ Psychological support is helpful.

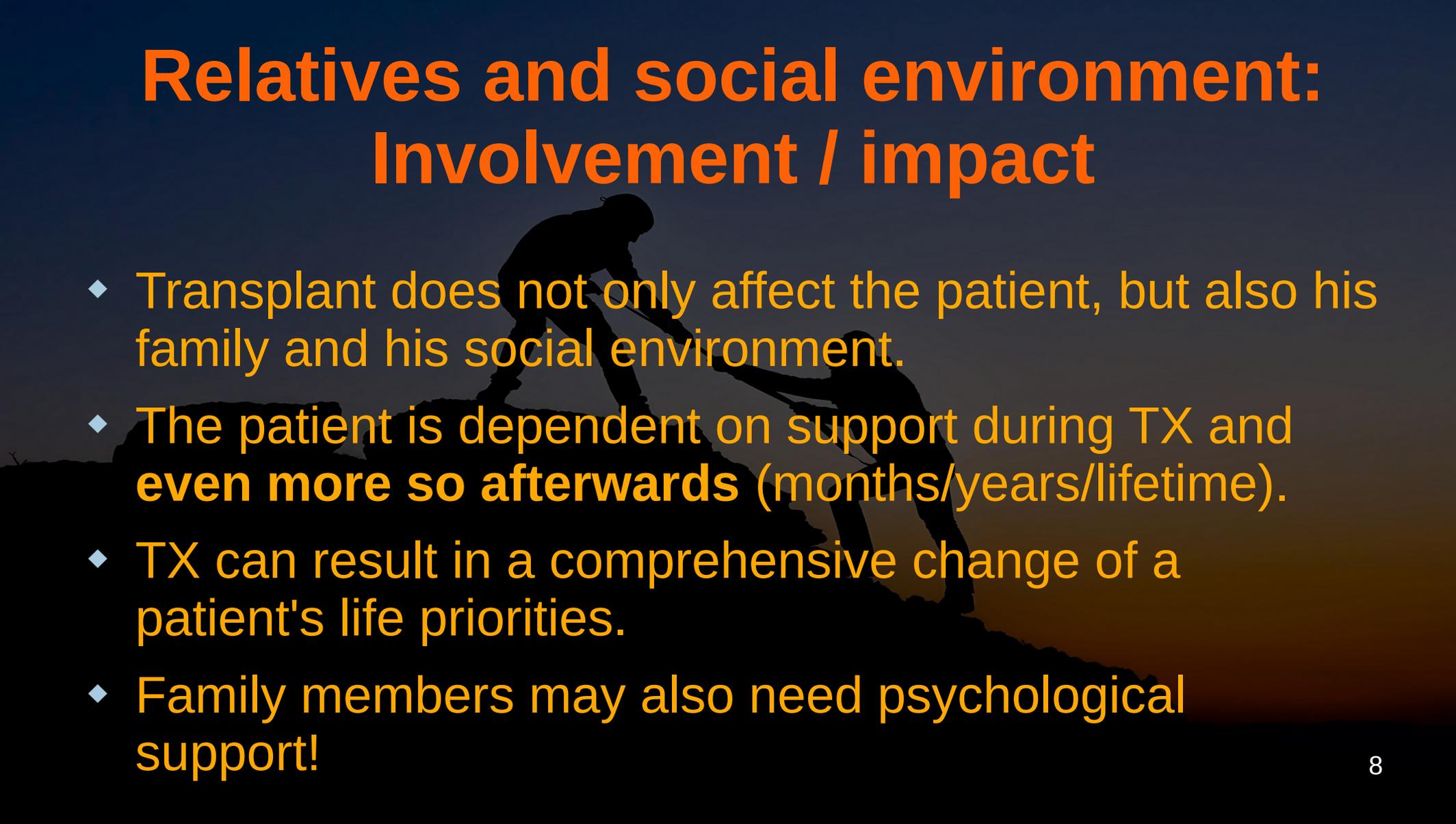
Considerations for the DECISION (1)

- ◆ In which phase is my MF? What is my score rating?
- ◆ What is the state of my health? Am I fit for transplant?
Age does not matter! What if my condition worsens significantly by waiting too long?
- ◆ How high is my level of suffering at the moment, possibly with the help of transfusions or drugs such as Ruxolitinib/Jakavi? What quality of life could be sacrificed by taking TX at this point?

Considerations for the DECISION (2)

- ◆ What about the risk that I might not be able to have a transplant later in life (e.g. no donor available) or that the MF might turn into AML?
- ◆ Can I "sit out" the MF due to my age? There are cases where the MF does not get worse for more than 10 years. What life span do I expect?
- ◆ Are there other reasons why the TX should be carried out right **NOW** or **NOT NOW**?

Relatives and social environment: Involvement / impact

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- ◆ Transplant does not only affect the patient, but also his family and his social environment.
 - ◆ The patient is dependent on support during TX and **even more so afterwards** (months/years/lifetime).
 - ◆ TX can result in a comprehensive change of a patient's life priorities.
 - ◆ Family members may also need psychological support!

Success!



I got rid of my myelofibrosis through the transplant, even though I needed a vital second transplant in 2012. I have been in remission since then with a good quality of life. I am committed to other patients and enjoy my life.

Anyone who is eligible for a transplant and manages to find a donor can also achieve this!



**Expect everything in
transplant,
including that it works!**

Thank you for your attention!

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