

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

Joachim **URMELT**, founder and co-administrator of
www.LENAforum.de

→ 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.

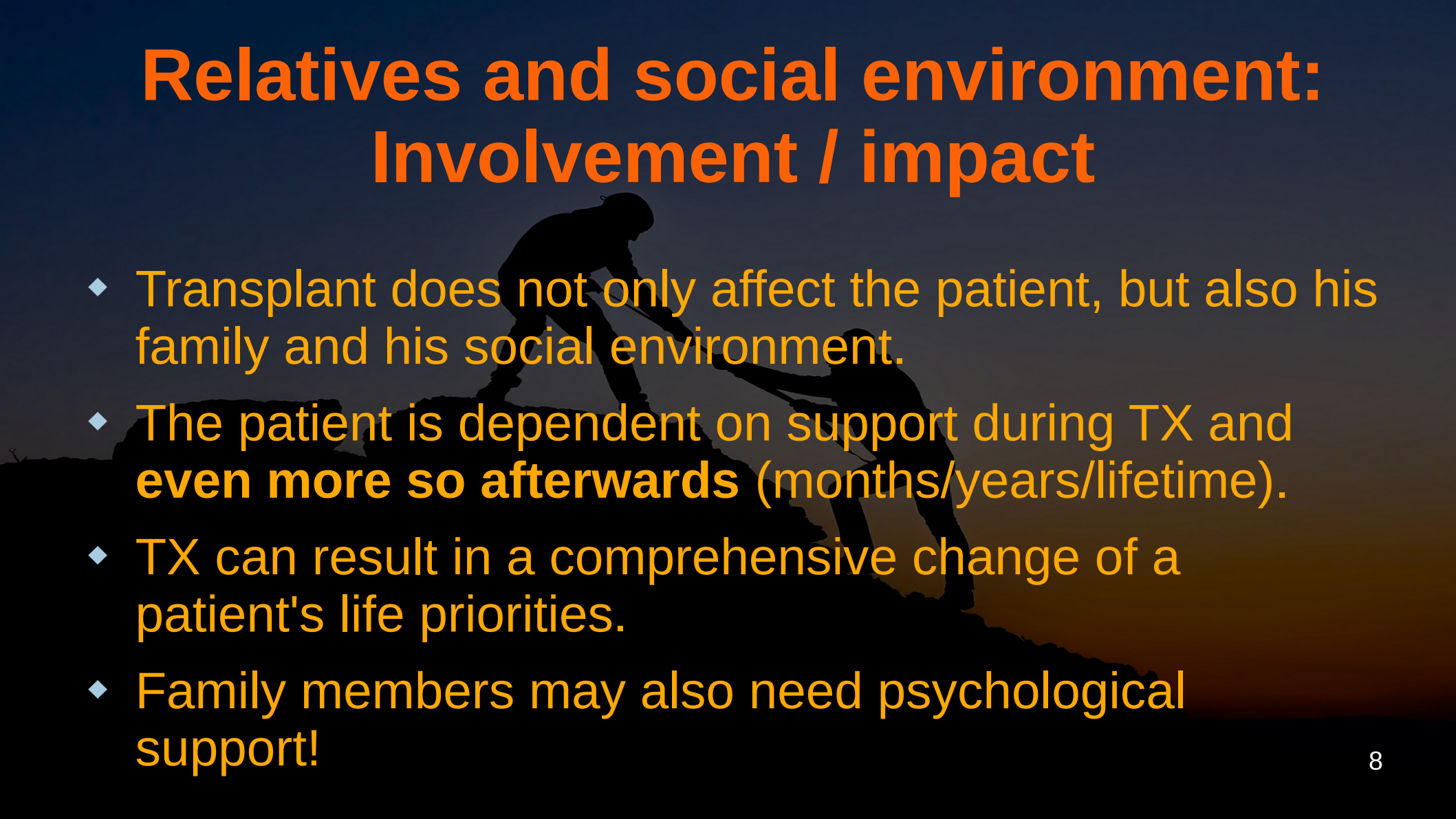
Considerations for the DECISION (1)

- ◆ 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

- 
- ◆ 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!

The background of the slide features a silhouette of two people climbing a mountain peak. One person is higher up the slope, leaning forward, while the other is lower down, also leaning forward. They appear to be using ropes or gear. The sky is a gradient of dark blue at the top to a warm orange and yellow at the bottom, suggesting a sunset or sunrise. The overall mood is one of triumph and perseverance.

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!

Joachim Urmelt - joachim.urmelt@lenaforum.de