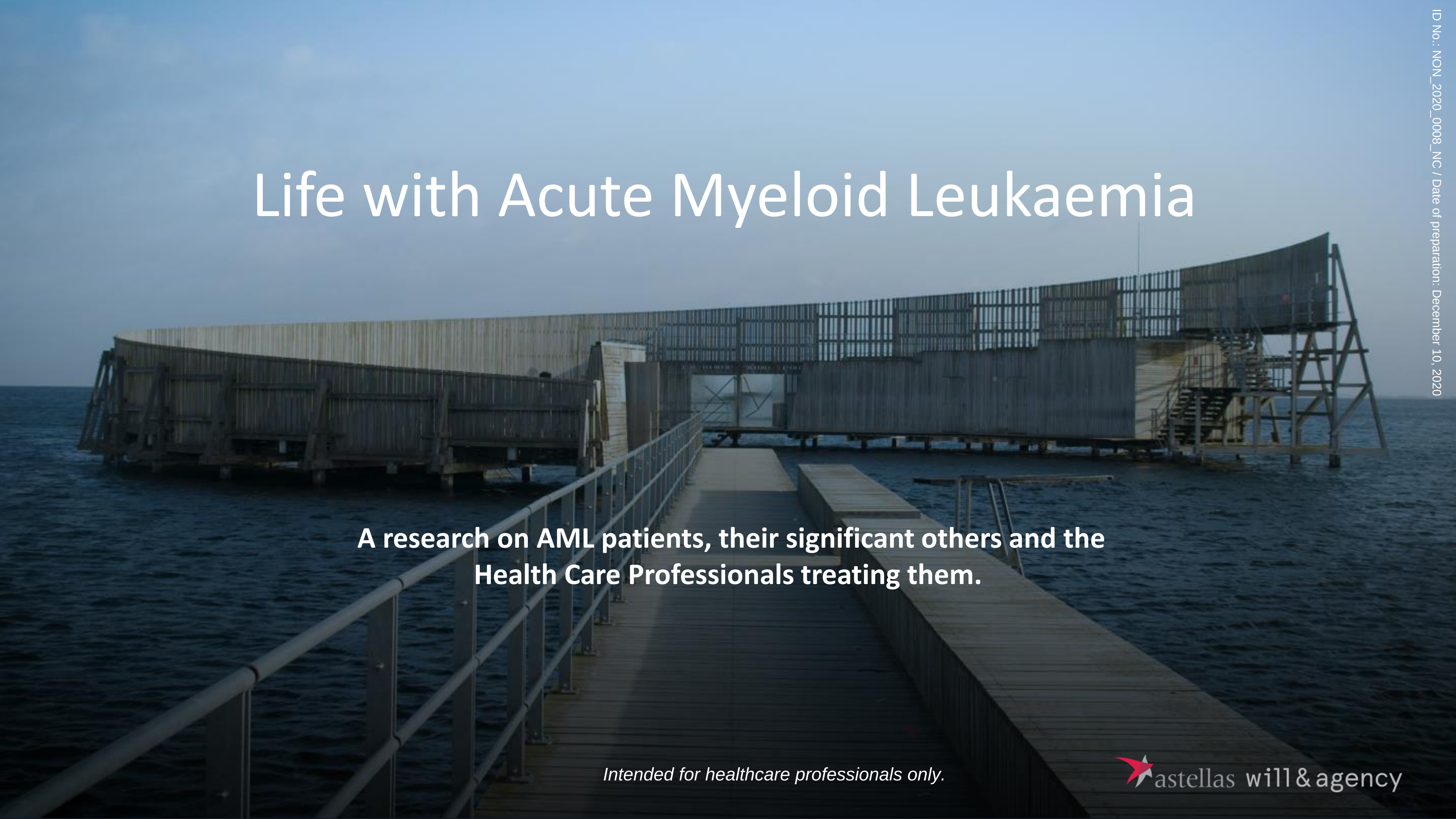

Life with Acute Myeloid Leukaemia

A research on AML patients, their significant others and the Health Care Professionals treating them.

Intended for healthcare professionals only.

astellas will & agency

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This report has been commissioned and financed by Astellas Pharma.

> “ Having acute myeloid leukaemia, it’s like pressing pause on life.
>
> \- male patient

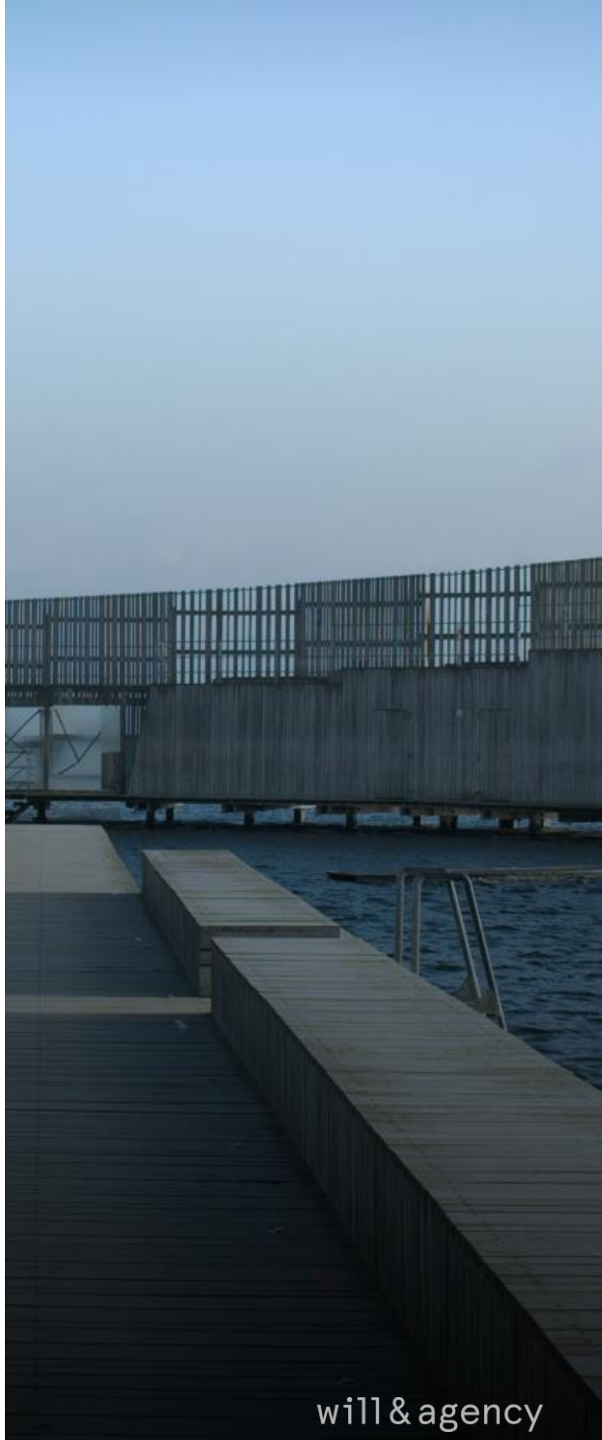
List of content

About this report

The report and the findings are based on insights from **17 qualitative interviews** with **six patients** living with Acute Myeloid Leukaemia (AML) and **three significant others** living with partners diagnosed with AML. In addition, interviews with **two nurses** and **six haematologists** have been conducted to understand the AML-treatment and the interactions between patients and hospital. The interviews were conducted in Sweden between May to October 2019.

The purpose of this research has been to generate new insights into how AML patients live and experience life with AML to better understand the needs these people have and face in their everyday life.

The report tells the story of people living with AML in their own words. All interviews have focused on experiences, feelings, motivations and thoughts on what it is like to live with AML, to live with someone who lives with AML and to work within the field of AML.



Executive summary

Three perspectives on life with AML

1 Patients

The patients participating in this research are between 49 to 73 years old. All have been through a relapse at some point in their AML journey.

They:

- Experience a high degree of social isolation.
- Experience transitioning to a new normal and a “new me” throughout treatment.
- Don’t talk much about feelings throughout the patient journey – they zoom in on the practicality of surviving.
- Live with a permanent unrest in the risk of facing a relapse.
- Feel closely connected to their treating HCPs.

2 Significant Others

The Significant Others in the research are spouses/partners to an AML patient.

They:

- Often engage very heavily in their partner’s treatment journey.
- Feel responsible for supporting the patient journey – and maintaining a sense of normality.
- Often forget themselves and their own needs in their strive to support their loved one.
- Often have to deal with a sense of physical isolation from their partner that the AML diagnosis creates.

3 Healthcare Professionals

The HCPs participating in the research all have more than 15 years of experience working with AML patients.

They:

- Are very engaged in their field and in their patients.
- Are frustrated about the lack of treatment opportunities in the field of AML.
- Are curious to learn more about the social dimensions of living with AML.
- See themselves as drivers of hope and motivation for the patients.
- Have different coping strategies that protect them from the emotional strain that comes with working with AML patients.

The anthropology of Nordic AML

Three analytical perspectives on the AML journey

1

Life as an AML patient

> **“Acute leukaemia is abstract, the patient doesn’t feel it. While it’s a very serious disease, it’s not a physical tumour in the head or a lump in the breast, that the patients can see and feel.**

- Haematologist

Being diagnosed with AML is experienced as pressing pause on life

When the patients are diagnosed with Acute Myeloid Leukaemia, there are many things they suddenly have to face and learn to navigate. It is a complex disease that is complex to live with.

It is a diagnosis that has sneaked up on the patients disguised as a heart problem, a lung disease, a cold or something else, but the patients never suspected something as serious as blood cancer. After being diagnosed, the patients start treatment within a couple of days.

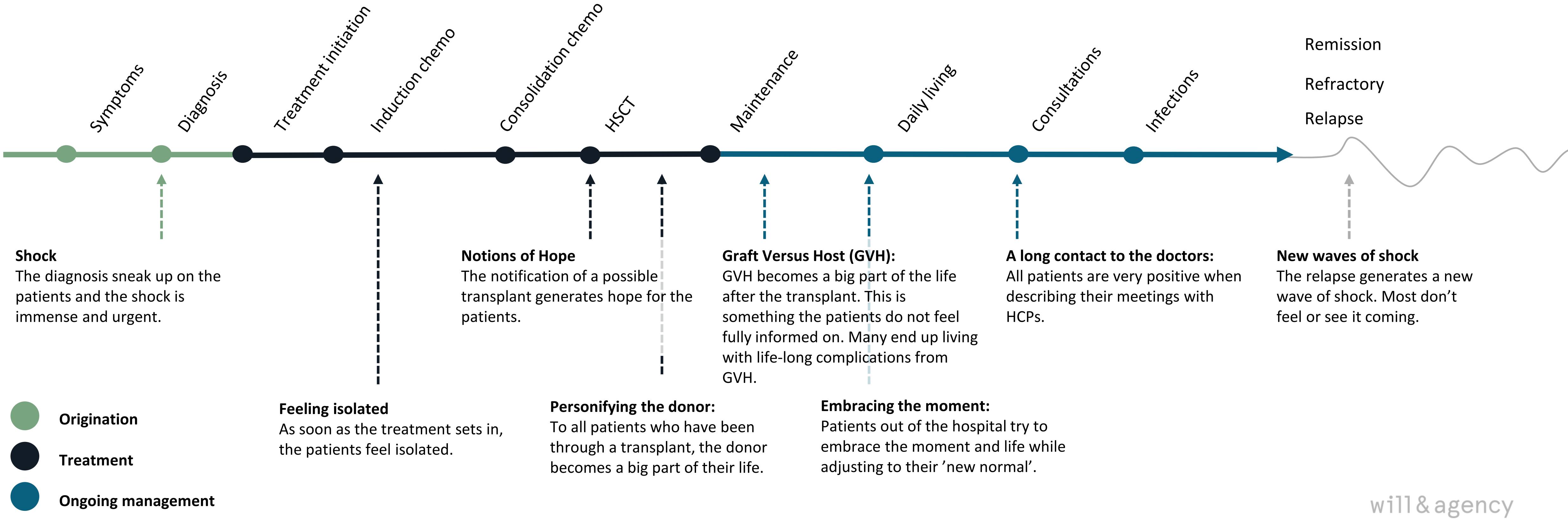
The patients experience **pressing pause** on their lives while being on treatment, because they spend a lot of time at the hospital and their focus is mainly on recovery. Normal life is set on hold and a life with AML begins.

In this period it is **not possible to engage in the same events, social gatherings or activities** as they used to due to their illness. The life as they know it is paused and a new and more narrow focus in life takes over. The patients describe that they *paused their normal life* to be able to transform the state of shock into a new normal and gradually figure things out.

In this period, it is all about **surviving** for the patients and they have a willingness to live with the health consequences and complications that follow the treatment.

The overall AML journey as experienced by the patients:

The overall AML journey has been divided into three critical steps by the health care professionals: Origination, Treatment and Ongoing Management. The patients, however, do not express their experience as three separate steps, but rather as **one journey with emotional and personal touchpoints.**



Shock
The diagnosis sneak up on the patients and the shock is immense and urgent.

Feeling isolated
As soon as the treatment sets in, the patients feel isolated.

Notions of Hope
The notification of a possible transplant generates hope for the patients.

Personifying the donor:
To all patients who have been through a transplant, the donor becomes a big part of their life.

Graft Versus Host (GVH):
GVH becomes a big part of the life after the transplant. This is something the patients do not feel fully informed on. Many end up living with life-long complications from GVH.

Embracing the moment:
Patients out of the hospital try to embrace the moment and life while adjusting to their 'new normal'.

A long contact to the doctors:
All patients are very positive when describing their meetings with HCPs.

New waves of shock
The relapse generates a new wave of shock. Most don't feel or see it coming.

● **Origination**
● **Treatment**
● **Ongoing management**

Shock
The diagnosis sneaks up on the patients and the shock is immense and urgent.

”I was in shock for the first two weeks. I thought I was dreaming. I didn’t believe that it was true- it was all so sudden. I just had a period with some infections and a cold, and then suddenly I had AML.” – male patient

”It was a shock for me to get the diagnosis. I was in chock for quite some time. There are many things from that period that I can’t remember.”
– female patient

Feeling isolated
As soon as the treatment sets in, the patients feel isolated.

”It’s like wearing a foot chain. You feel like a criminal being punished. You can’t go out, you can’t go do groceries, you can’t go out for dinner”
– male patient

Notions of Hope
The notification of a possible transplant generates hope for the patients.

”The 5th of June, the day of my transplant, is almost more important to me than my birthday” – female patient

Personifying the donor: To all patients who have been through a transplant, the donor becomes a big part of their life.

”I find it so boring to say ”the donor”. I know it’s a woman from Germany, so I call her Hildegard” - female patient

Graft Versus Host (GVH):
GVH becomes a big part of the life after the transplant. However, many live with life-long complications from GVH.

”Now I’m thinking more about the GVH than that I have had cancer”- female patient

Embracing the moment:
Patients out of the hospital try to embrace the moment and life while adjusting to their ’new normal’.

“It’s important to me to seize the day and enjoy the flowers and nature”- female patient

A long contact to the doctors:
All patients are very positive when describing their meetings with HCPs.

"I leave it to the doctors. I trust them. Some read their medical journals but I don't want to. I don’t understand why you would do it. You don’t get cured by reading it."
- male patient

New waves of shock
The relapse generates a new wave of shock. Most do not feel or see it coming.

"I had just built a stonewall. I could not believe that I was ill. It took me completely by surprise. I did not feel ill at all. I thought, you don’t just build a stonewall when you are ill. But they assessed that there was 18% cancer cells. So it was a relapse."
- female patient

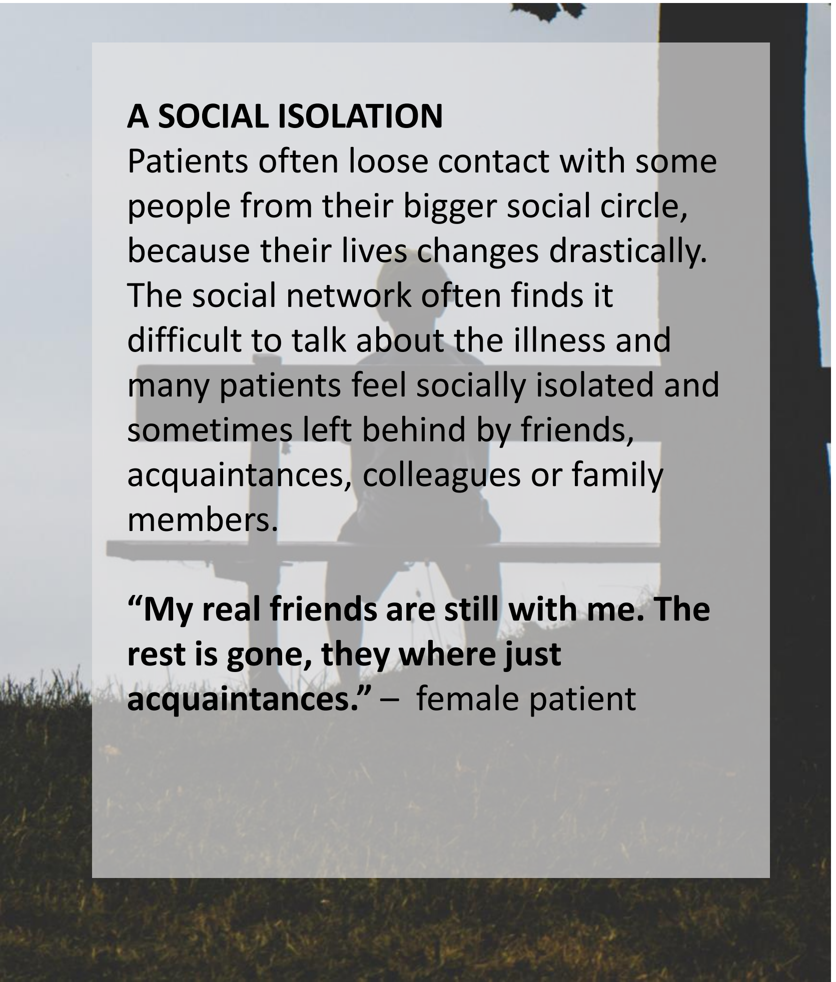
● **Origination**

● **Treatment**

● **Ongoing management**

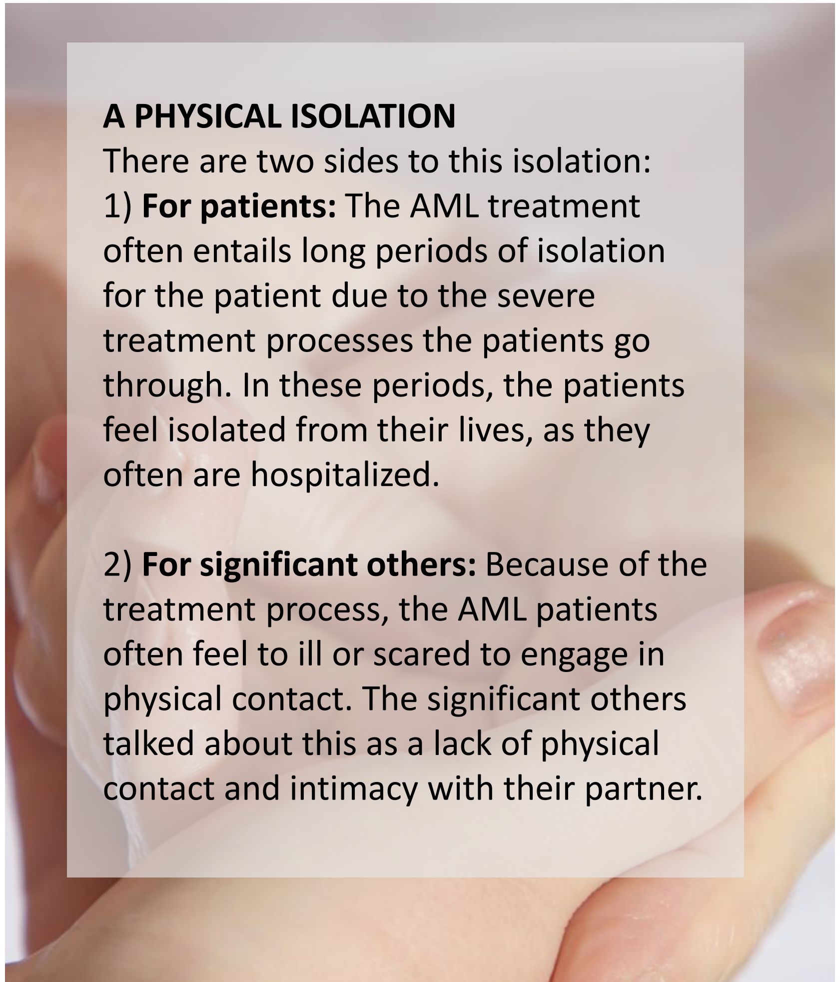
Isolation becomes an inevitable part of life

To many of the interviewed patients, isolation has become a big part of the daily life of AML. Either manifested in the shape of feelings of a social isolation, a physical isolation or as a fear of *not* being isolated.



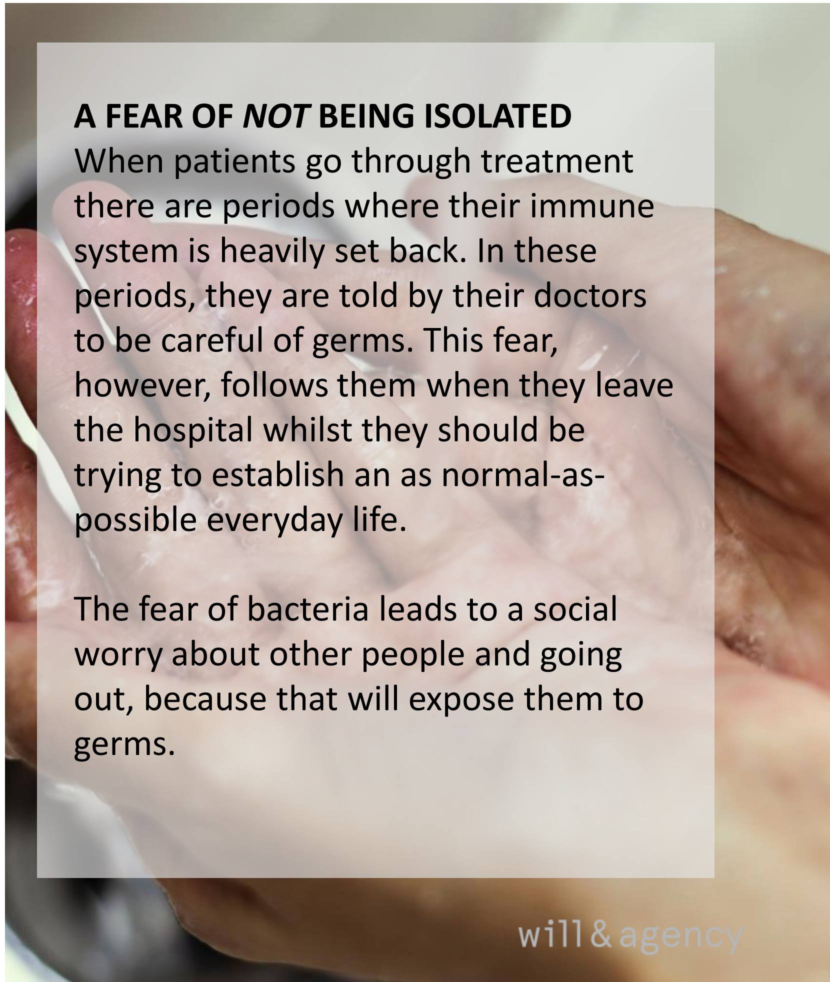
A SOCIAL ISOLATION
Patients often loose contact with some people from their bigger social circle, because their lives changes drastically. The social network often finds it difficult to talk about the illness and many patients feel socially isolated and sometimes left behind by friends, acquaintances, colleagues or family members.

"My real friends are still with me. The rest is gone, they where just acquaintances." – female patient



A PHYSICAL ISOLATION
There are two sides to this isolation:
1) **For patients:** The AML treatment often entails long periods of isolation for the patient due to the severe treatment processes the patients go through. In these periods, the patients feel isolated from their lives, as they often are hospitalized.

2) **For significant others:** Because of the treatment process, the AML patients often feel to ill or scared to engage in physical contact. The significant others talked about this as a lack of physical contact and intimacy with their partner.



A FEAR OF *NOT* BEING ISOLATED
When patients go through treatment there are periods where their immune system is heavily set back. In these periods, they are told by their doctors to be careful of germs. This fear, however, follows them when they leave the hospital whilst they should be trying to establish an as normal-as-possible everyday life.

The fear of bacteria leads to a social worry about other people and going out, because that will expose them to germs.

UNDER TREATMENT, EVEN FAMILY LIFE CAN BE SET ON PAUSE:

> “I didn’t even see my daughters and grandchildren in the time I was hospitalized. They could risk infecting me, so they couldn’t come visit”
>
> - male patient

The patients learn to become patients

During treatment, the patients have to understand themselves under their new circumstances as a patient. To be an AML patient is not just something you are, but also **something you learn to be**.

By taking small steps and only focusing on the next task at hand, the patients have learned to navigate in the treatment process and how to be “a patient”.

After treatment, the AML patients are not the same person anymore because of new limitations and experiences that has formed them. Therefore **they need to redefine themselves and their “new normal”.**

”The patients grow in accordance with the task. Most of them do really well with the challenge of being a patient. It’s not all, but it’s a lot. It’s impressive to see.”

- Haematologist

And they have to find themselves throughout the patient journey

”I have changed both mentally and physically, but sometimes I think that I want my old self back.”

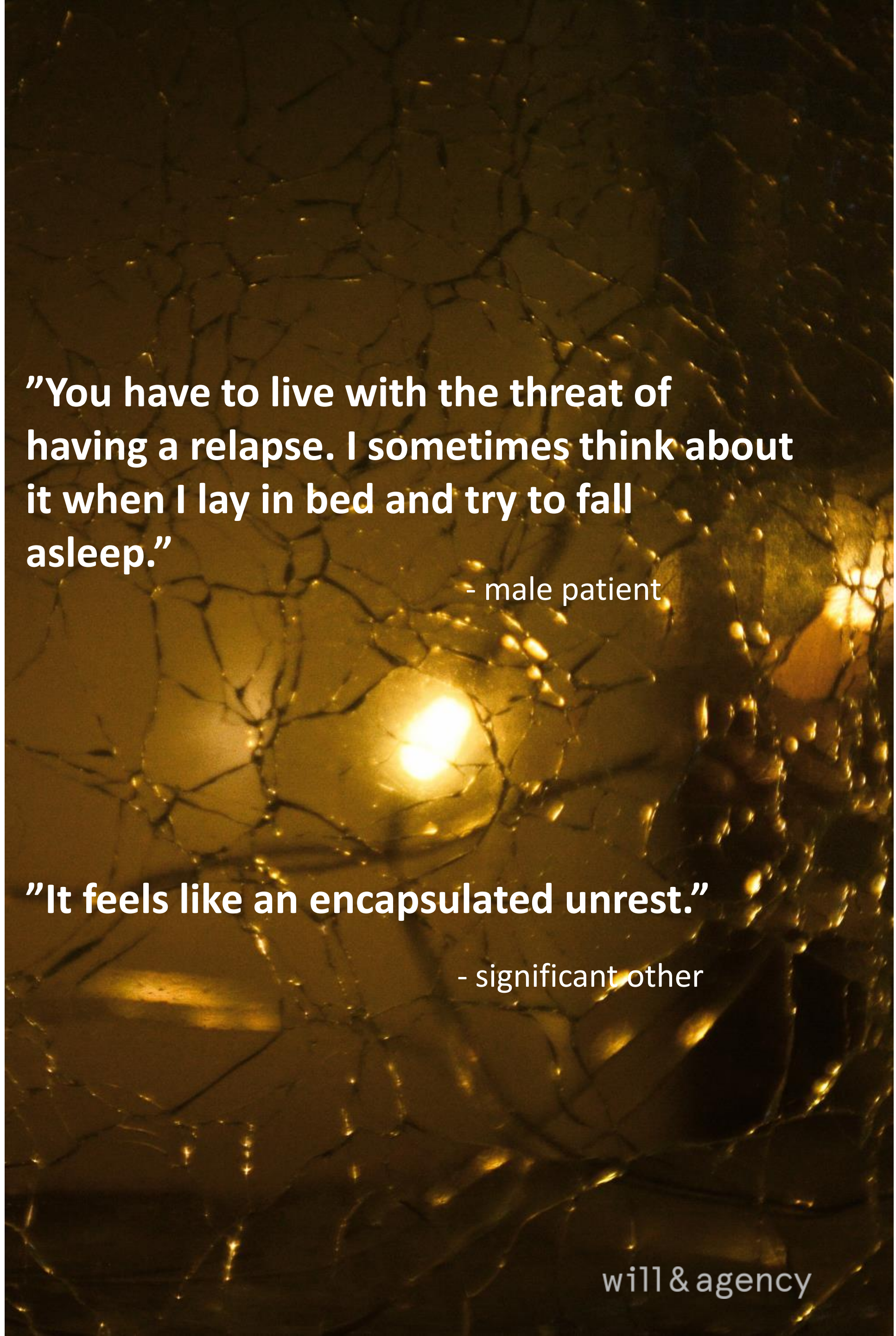
- female patient

Throughout it all, they face a permanent unrest

Both patients and significant others point to AML as something **constantly luring in the background.** The AML-diagnosis came as an unexpected shock to all patients and and even throughout treatment in the attempt to make a life, the thought of AML never leaves.

The patients explain how they live in **a constant state of unrest** that follows them throughout their patient journey – even when there are no cancer cells and they have been cancer free for many years.

The patients constantly worry that the disease will come back at any time. Even many years into remission, patients and significant others still feel an “encapsulated unrest”. This term relate to the understanding of AML as an invisible disease encapsulated within the cells, which also encapsulate the feelings of unrest. The patients feel scared and worried if they feel ill, have a cold or have an infection.

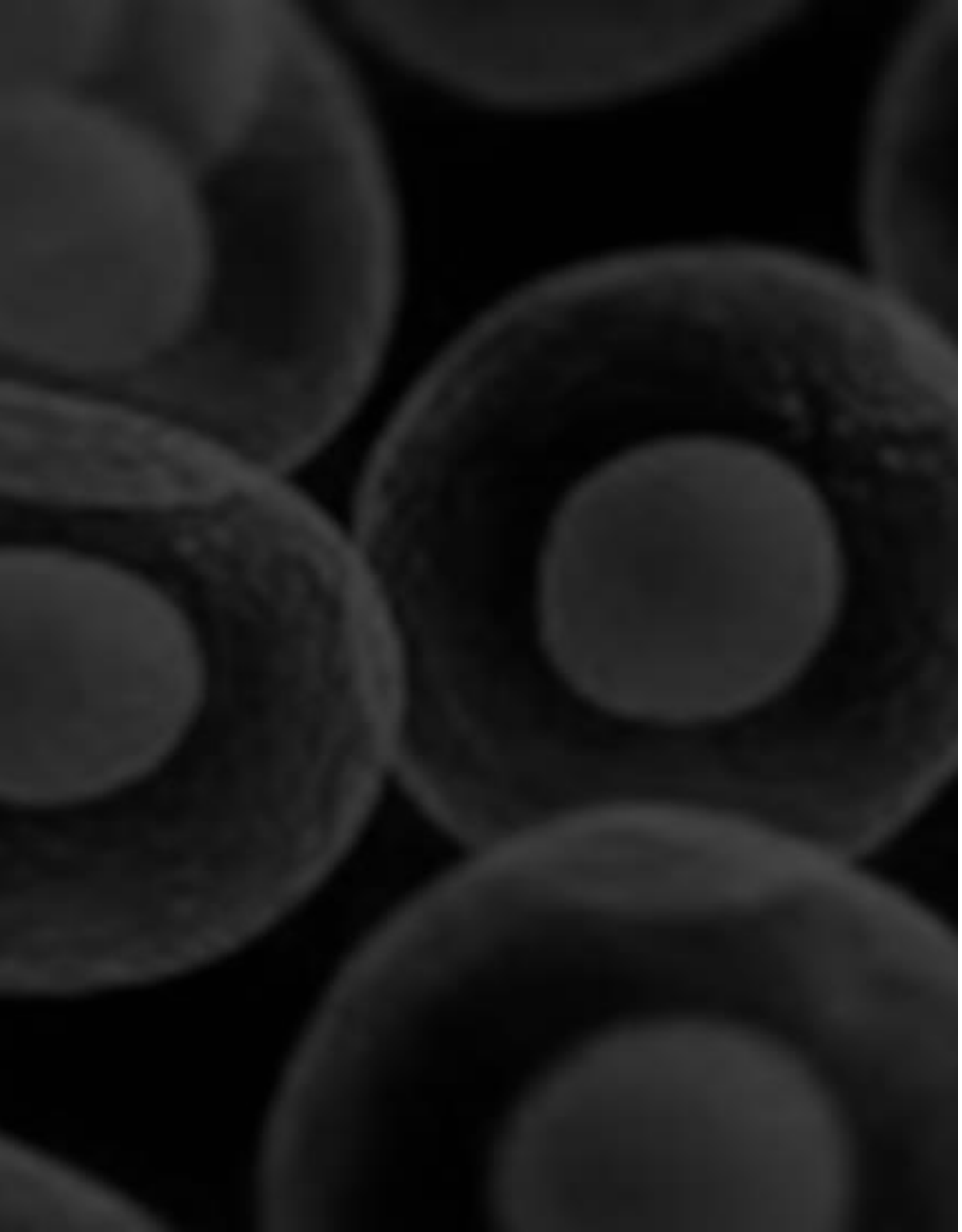


”You have to live with the threat of having a relapse. I sometimes think about it when I lay in bed and try to fall asleep.”

- male patient

”It feels like an encapsulated unrest.”

- significant other



THE POSSIBILITY OF A RELAPSE ALWAYS FEELS PRESENT:

"It only takes one little devil [cancer cell] somewhere in the body that begins to stir."

- significant other

The disease has a social ripple effect

The disease also has a strong impact on the patients' social life and AML affect the patients' family and friends.

For some patients, **the AML drives them close** to their loved ones and family because the disease is seen as something the family as an entity should tackle together. The disease further enables conversations on vulnerability and the life-changing situation the whole family is facing and the many emotions related to it.

To other patients, however, **the disease and the diagnosis create a social distance** to their family and social circle. Many of these patients find it hard to talk about their disease and as a result, they decide not to share their illness, treatment or emotions with some members of their family or even the family as a whole. This can be seen as a way to protect the family – and especially children living at home.

"You get another family life when you go through something like this. We are much closer now and she [patient] is much closer to her daughter as well."

- significant other

"I didn't want to show to my children that I was sad. I put on a mask when they came to visit. When everybody had left I sat in bed and cried. I also remember standing in the shower crying."

– female patient

5 ways of coping with AML

How the patients cope with the disease

When the AML patients talk about their experiences of living with AML and their everyday life, they often talk about how they cope with the disease in different ways. It can be everything from small techniques, strategies to simple distractions depending on the individual person, the treatment process and the context. However, we have identified five common strategies all applied in daily life to make life with AML a little easier to deal with.

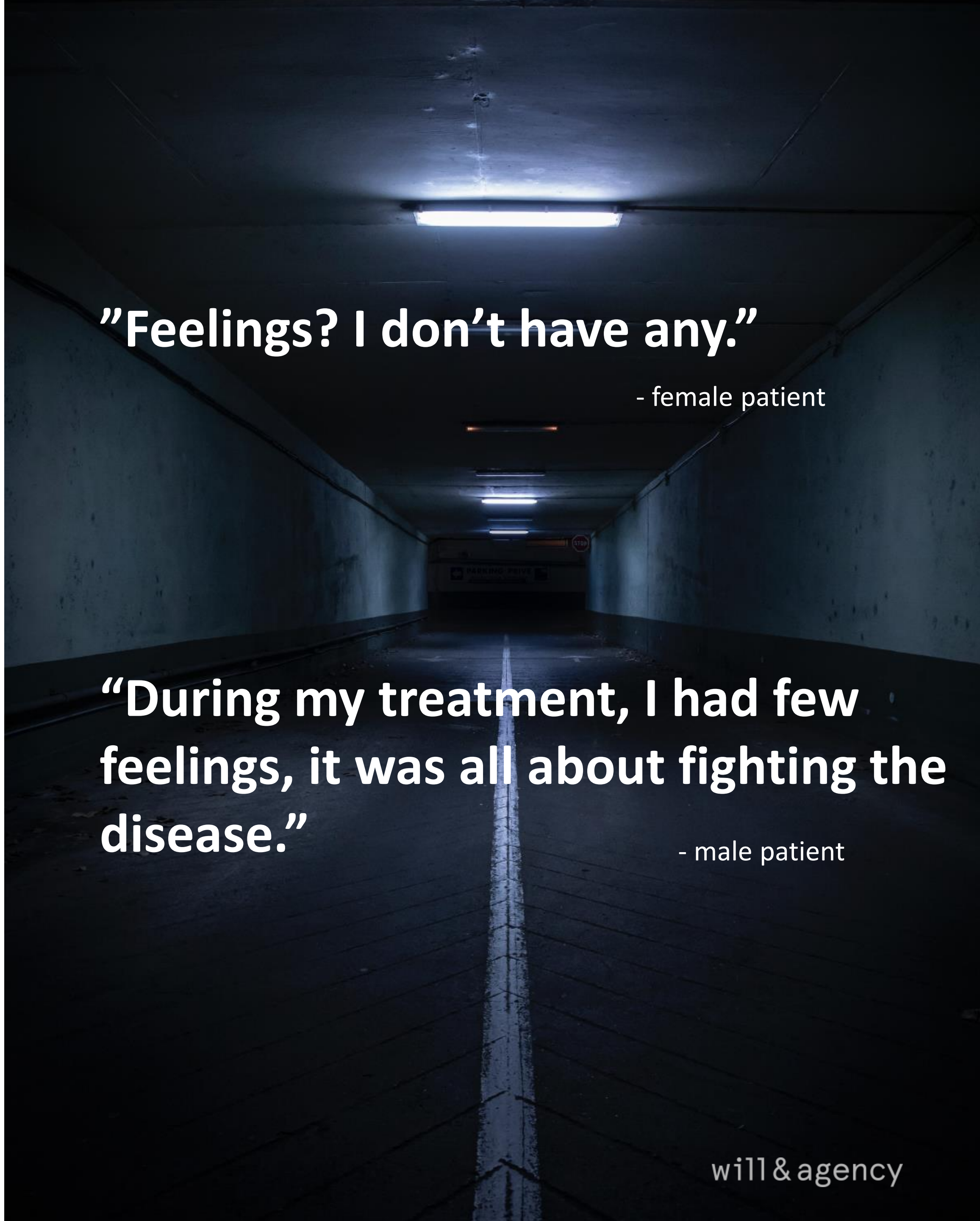
1. **Tunnel vision as a strategy**
2. **Different ways of knowing as a strategy**
3. **Escapism as a strategy**
4. **To make or break the isolation as a strategy**
5. **AML network as a strategy**

1. Tunnel vision

Amongst the patients, the emotional AML journey is often described as being a limited fluctuation between emotions or as moving through a tunnel.

In the Nordic AML journey, however, there are periods where no feelings are present or expressed. It is possible that a roller coaster of emotions takes place within the patient, but it is something experienced internally, and not necessarily something expressed externally. This can be explained by a more toned—down Scandinavian approach to addressing emotions in public.

In the *tunnel* you only focus on the recovery on the other side and do not engage with the emotional aspect of the journey. Another way this tunnel manifests itself is when the patient is being “egoistic” or “self centered” (patients’ wording) during the patient journey. In this period, they do not engage as much in the needs or feelings of their significant others, because they focus on their own recovery.



”Feelings? I don’t have any.”

- female patient

“During my treatment, I had few feelings, it was all about fighting the disease.”

- male patient

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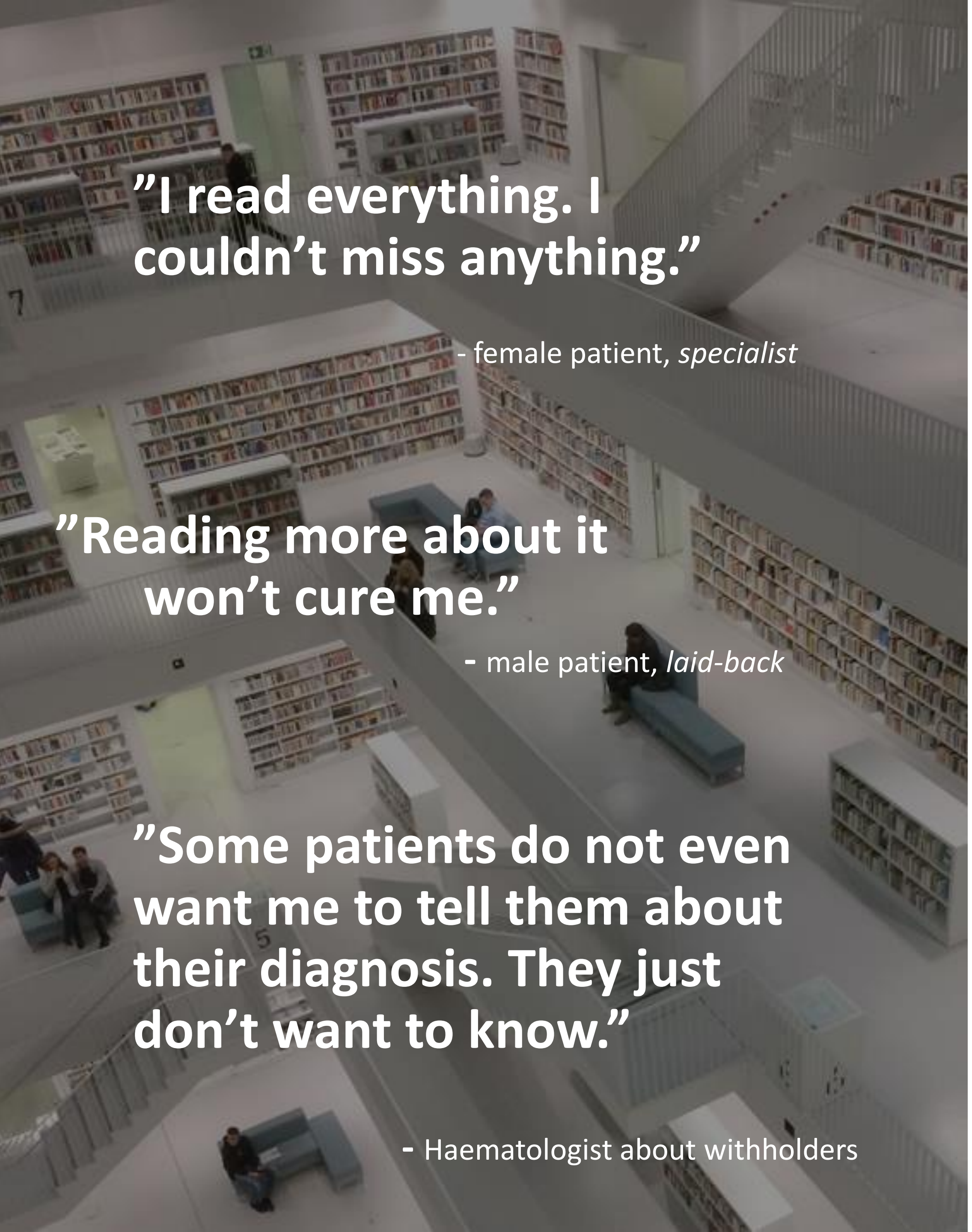


”I read everything. I couldn’t miss anything.”

- female patient, *specialist*

”Reading more about it won’t cure me.”

- male patient, *laid-back*

”Some patients do not even want me to tell them about their diagnosis. They just don’t want to know.”

- Haematologist about withholders

2. Different ways of knowing

The AML patients engage in different ways when they seek information on their diagnosis and treatment. Three types of information seekers (and significant others in some cases) have been identified moving on a continuum from a passive approach to an engaged approach. The three identified mindsets indicate different ways of coping with getting information about diagnosis, treatment and medicine.

”THE SPECIALISTS”
This type seeks out as much information as possible on diagnosis, trials and different treatments.

”THE LAID-BACKS”
This type does not actively seek out information and rely on and have faith in the HCP information.

”THE WITHHOLDERS/CLOSED”
This type gives the full authority to the HCP and does not want to know anything or little to nothing about specifics of diagnosis, trials and different treatments.

3. Escapism as a strategy

Living with AML often means living with many constrains. One of these constrains is the long periods of hospitalization that many patients go trough. Many of the AML patients cope with their illness by *fleeing* from their mental and physical constrains. They do this by trying to **distract themselves** and create a life that resembles the life they used to live before the illness as much as possible.

The patients do this by removing themselves from the hospital setting by:

- taking walks
- mentally taking their mind of the illness by preoccupying themselves with something else
- doing small work-outs
- watching TV for hours (and hours).

"I worked everyday I was hospitalized. That was my way of maintaining a sense of normality."

- male patient

"I brought him all (the) food, it was also our cutlery from home that he was using – then it felt as much like home as possible."

- female significant other

LEAVING THE HOSPITAL CAN CREATE A SENSE OF REALITY:

“ When I was hospitalized I walked around the city early in the morning before every one came to the streets. Then I’d stop by my work and write small notes for my colleagues. That was probably my way of being in contact with reality.”

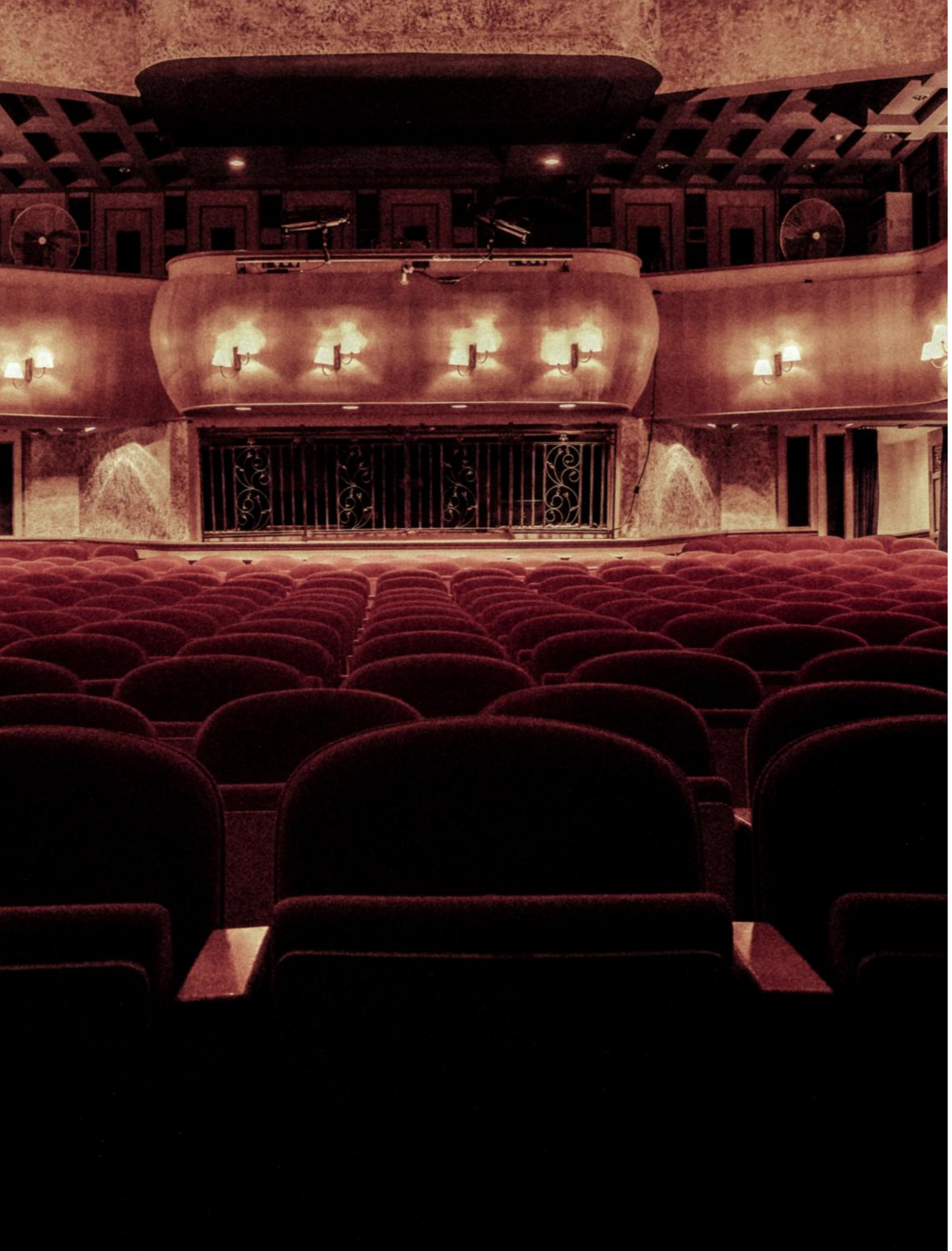
- male patient

4. Creating or breaking the isolation

Life with AML holds many worries. One of these is the fear of infections and bacteria and **isolation is a key word for AML patients.** The patients learn from their treating haematologists that they have to be careful with bacteria and physical contact when diagnosed with AML, as their immune system is set back. The patients cope with this in two ways:

a) **CREATING THE ISOLATION**
Some patients decide to stay mostly at home. These patients cut themselves out of different activities they would normally participate in and they often isolate themselves from relatives and friends during the treatment to protect themselves.

b) **BREAKING THE ISOLATION**
Some patients, however, do not want to accept these physical restrains that the diagnosis bring. They create other ways to connect with family and friends, that does not include as much physical contact, these patients insist on trying to live a normal life as possible.



SOME PATIENTS GIVE UP ON OLD HABITS TO ENSURE ISOLATION:

“We didn’t go out for dinner or big events for a long time after I was discharged. It was a kind of paranoia that we had. When we were out, we heard all the people coughing in our proximity. It took several years before we went to the theater again.”

- male patient

OTHER PATIENTS FIND NEW WAYS TO BE SOCIAL TO BREAK ISOLATION AND BE CLOSE TO FAMILY:

> ”I couldn’t *not hug* my grandchildren, so we invented this air hug, so we could send each other hugs through the air”

- female patient

5. Being part of an AML network

Social networks between AML patients can be seen as **a double edged sword** that can give both comfort and support, but it can also be strenuous. As a result, some patients choose to engage in networks as a strategy for support, while others actively choose to restrain from these networks as a strategy to protect themselves.

To some patients, it is important to have contact with other AML patients because it gives the opportunity to feel supported and share their experience, information and strategies with people who deal with the same illness and treatment. To these patients, the network gives support.

At the same time, AML patients can also feel that it is complicated to get to know other AML patients, because it is difficult not to compare your own health journey with others, and that can be emotionally straining, as it can create more fear and insecurity in one's own journey. Because AML patients are high risk patients it is common that people in the network get worse, relapse or even die. This can be a lot to handle in a time where the patients themselves have to deal with their own mortality.

2

Living with an AML patient

Everybody needs someone for their someone.

The significant other often plays a vital role

The AML diagnosis does not only affect the patient but also the social life and surroundings of the patient. In most cases, the patient is surrounded by a network that has to learn to navigate in the new circumstances which come with the disease.

As such, the disease has an effect on how the patient, their loved ones and the bigger social circle interact and communicate. Therefore, it is not only the patient that has to learn to be “a patient”, but also **the network around the patient that has to learn to be “a significant other”.**

Being the significant other to an AML patient can be an enduring time, as **they are playing several roles at the same time**. They become caretakers, housekeepers, secretaries, eyes and ears of the patient, researchers, cheerleaders and partners to mention a few. The significant others in this research explain how they often feel overlooked in the process although playing vital roles.

This section offers the significant others a channel to voice *their* experiences with living with an AML patient from *their* perspective.

Emotional touchpoints for the significant others

Like the patients, the Significant others do not necessarily perceive of the AML journey as divided into the three steps. They rather experience the journey based on experienced emotional milestones related to the treatment.

Shock from diagnosis:
The significant others feel a big shock when their loved ones get the diagnosis. This has to do with the acuteness and unexpectedness of the diagnosis.

Hope:
After the treatment has been commenced, the significant others start to let the hope grow.

Threshold:
The transplantation seems like an important threshold for the significant other as it marks a possible outcome of the treatment. It, however, also represents a possible threat.

New obstacles:
The aftermath of the transplantation represents new and very unexpected complications and challenges that can feel strenuous.

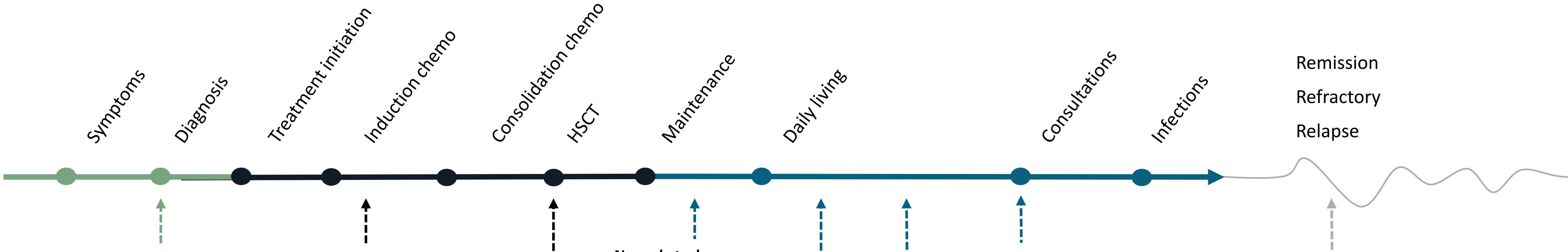
Embracing the moment:
Because of the high risk associated with AML, the significant others take nothing for granted and try to make the best of life.

Feeling physically isolated from partner:
Many of the significant others feel deprived of physical contact with their partner.

In good hands:
The significant others feel that the hospital staff are doing a good job.

New shock from relapse:
When the relapse comes the significant other experiences a new shock.

- ● **Origination**
- ● **Treatment**
- ● **Ongoing management**



Symptoms

Diagnosis

Treatment initiation

Induction chemo

Consolidation chemo

HSCT

Maintenance

Daily living

Consultations

Infections

Remission

Refractory

Relapse

Shock from diagnosis:
The significant others feel a big shock when their loved ones get the diagnosis. This has to do with the acuteness and unexpectedness of the diagnosis.

“It was so to speak a death sentence. It was catastrophic.”
– male significant other

Hope:
After the treatment has been commenced, the significant others start to let the hope grow.

”After the chemo, I thought now he is cured”
– female significant other

Threshold:
The transplantation seems like an important threshold for the significant other as it marks a possible outcome of the treatment. It, however, also represents a possible threat.

”It was important to me that we were together and that I was part of the transplantation journey.”
– female significant other

New obstacles:
The aftermath of the transplantation represents new and very unexpected complications and challenges that can feel strenuous.

”When she had that GVH, I thought, will this never end?”
- male significant other

Embracing the moment:
Because of the high risk associated with AML, the significant others take nothing for granted and try to make the best of life.

”You don’t know if you see each other the next day. That is why I want to do the best every day."
- female significant other

Feeling physically isolated from partner:
Many of the significant others feel deprived of physical contact with their partner.

”It is difficult not having sex with my wife, we cant because of the complications.”
- male significant other

In good hands:
The significant others feel that the hospital staff are doing a good job.

"I have trusted that they do their best. I have to trust that they do their best.”
- male significant other

New shock from relapse:
When the relapse comes the significant other experiences a new shock.

”After two years, we toasted with the children and celebrated that the disease was gone. Two weeks later we were informed that he had a relapse. It was a total surprise. Now we don’t have the courage to toast anymore.” – female significant other

”By now, we have become specialists within the field.”

- male significant other, insider

”My boyfriend worked a lot during the treatment and played golf. I think he needed to distance himself.”

- female patient on her boyfriend, outsider

There are different ways of being part of the patient journey

Just like the AML patients has their ways of coping with AML, the significant others have different coping strategies for dealing with their loved one’s illness and being a part of the journey throughout the treatment process. Amongst the significant others, two prototypical tendencies have been shown. These should be understood as being on a continuum:

THE “INSIDER”
By seeking out as much information as possible and being very involved in the treatment process practically and/or in terms of knowledge seeking, the significant other takes on the role as an ”insider”. This is a way to be in control and better understand the situation. They often take on a role as an extra pair of eyes and ears for the patient and translate the haematologists’ word, when the patient is in too much of a shock to hear or acknowledge.

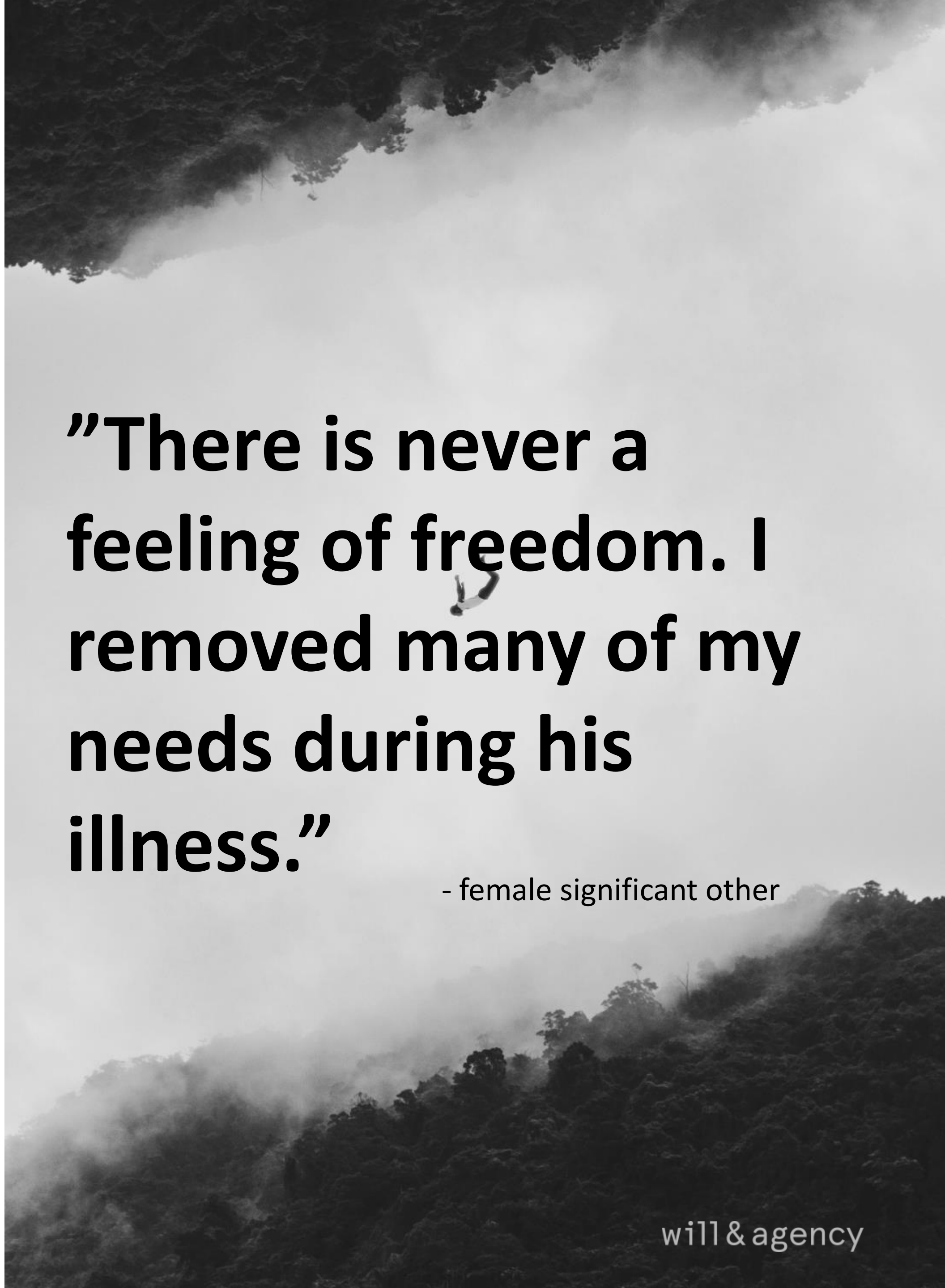
THE “OUTSIDER”
By not actively seeking out information and being less or not at all a part of the treatment process, the significant other becomes an ”outsider”. This is a way to protect yourself by not knowing the high risks involved with the illness.

Sometimes the significant others loose themselves during the patient journey

As a result of their high level of engagement in the patient’s journey and treatment, the significant others often **loose themselves**, while devoting their time, love, life and energy to their sick partner.

In combination with the very individually focused patient journey - where the patients themselves – and a treatment process where the health care professionals often zoom in on the patient’s needs only – **the needs of the significant others are often unattended and for some quite invisible.** It seems, that AML does not make room for anything else but the patient.

When asked about their experience, the significant others feel a sense of relief, because it is uncommon for them to be asked about this. They are used to stand in the background through the patient journey and tell the story of the AML patient instead of their own. Usually, all focus is devoted to the patient and the significant other has to be the strong part.



”There is never a feeling of freedom. I removed many of my needs during his illness.”

- female significant other

SOMETIMES, THE SIGNIFICANT OTHERS ONLY BECOME VISIBLE WHEN THINGS GO WRONG:

”It’s important that the patient becomes selfish in the situation. Sweden is a very individualistic country, and maybe we’re not always good at informing relatives. Maybe we [the health care professionals] are too bad at thinking about the family as an entity, when treating the patient. We often feel this, when the treatment goes bad.”

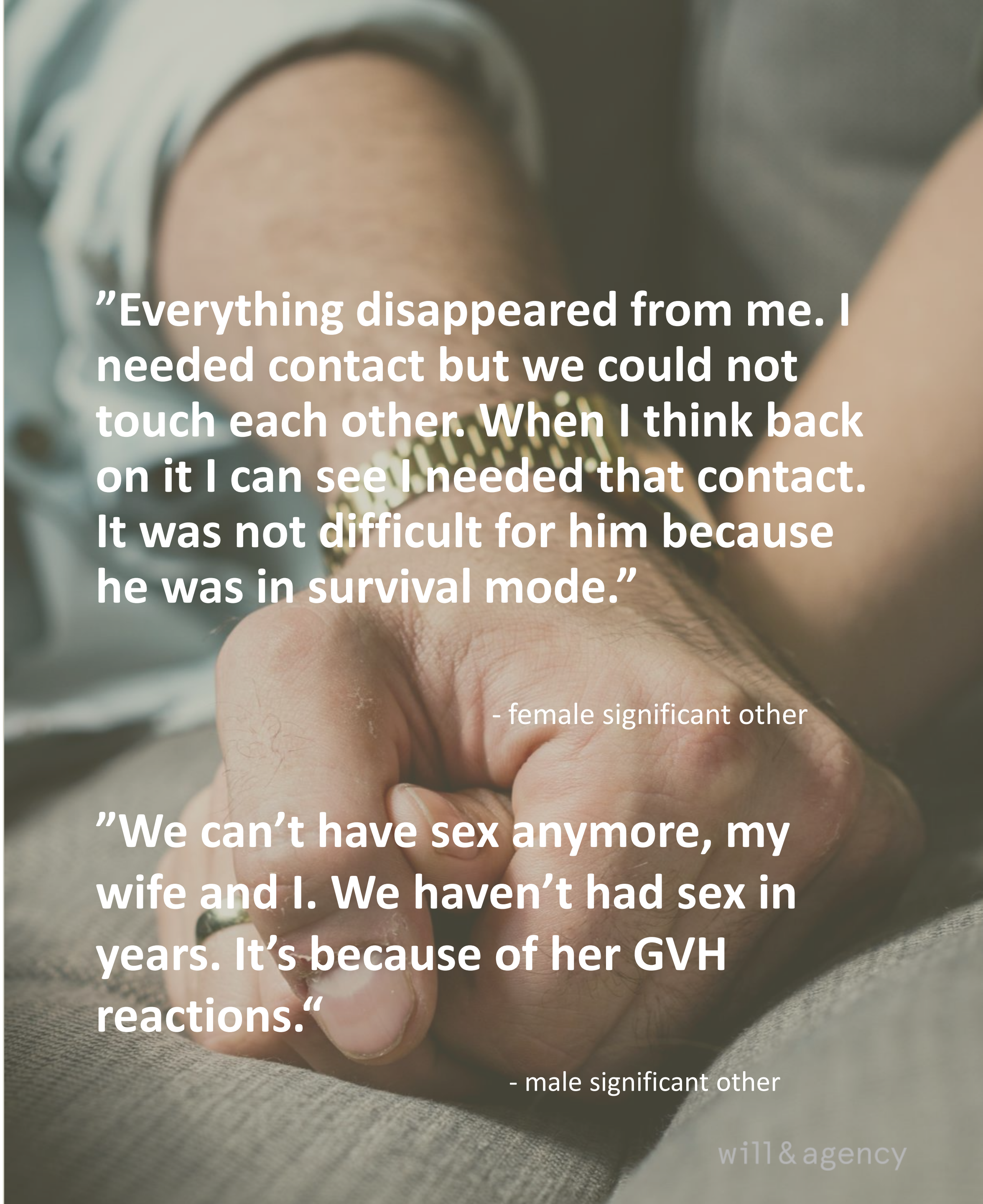
- Haematologist

They experience physical isolation from their partner

As it was for the patients, **isolation is also a key word for the significant others.** An AML-diagnosis changes many elements in the patient's life, why these changes are also experienced by the significant other. Living with an AML patient, the significant other come to sense a lack of physical intimacy with their partner.

The patients often feel too ill or scared to engage in physical contact either as a result of the diagnosis and treatment or GVH-reactions. Some significant others talk about this lack of physical contact, intimacy and sex with their partner as a feeling of **physical isolation**, which can be difficult for them to cope with.

The lack of intimacy also showcase the big life changes they and their partners have been through. Going back to having more physical contact would restore a life that resembles the life they had *before* their partner got cancer.



"Everything disappeared from me. I needed contact but we could not touch each other. When I think back on it I can see I needed that contact. It was not difficult for him because he was in survival mode."

- female significant other

"We can't have sex anymore, my wife and I. We haven't had sex in years. It's because of her GVH reactions."

- male significant other

For some, companionship can be a help

It can be helpful to talk about ones experience and the significant others have felt alone and often isolated in their partner's AML journey.

In fact, many of the significant others participating in this research felt relieved when asked about their perspective and experience. They were so used to explaining everything from the patient's perspective.

When talking about what kind of support, a significant other could benefit from, social networks were mentioned. One of the participants had rich experiences from taking part in a support group with likeminded and found a great deal of comfort and support in talking about feelings and experiences with other significant others going through similar processes.

However, as it was the case for the patients, the social networks are also seen as **double edged swords** that can give both comfort and support, but it also be a strenuous and hard experience. Being in a vulnerable position it is easy to compare or mirror your own experiences with others. This constant comparison can be emotionally straining, as it can create more fear and insecurity in one's own journey.

3

Working in the field of AML

Hyper engaged but careful.

Touchpoints for the haematologists

Relief
The nurses describe a feeling of relief when the diagnosis has been given, as this enables them to act.

"When the diagnosis has been given, I feel relieved, as I know what we have to do to help the patient."- nurse

Test frustration:
Some haematologists wait up to 4 weeks before getting the specific results. This affects the patients treatment possibilities.

"It can take 4 weeks before I get the results from the lab on the mutation. By then, the patients have already started a standardised treatment - haematologist

Day 25:
On day 25, doctors and nurses know how a patient reacts to the given treatment. This day affects how the future treatment for the patient unfolds.

"By day 25, we know how the patients have reacted to the specific treatment. At this point, we will know more about the future" - nurse

Transplantation:
The haematologists transfer the patients going through a transplant to a different section. Therefore they are out of reach with the patients in this period.

"We don't see them much around this time. They are with our colleagues. I don't know how they talk to the patients about possible GVH, actually. After the transplant, they will come back to us for consultations"- haematologist

Curiosity:
Haematologists are curious to how their patients live their lives outside the hospital.

"We are doing these practical things at the hospital, but we cannot imagine everything what they are going through outside. How could we tackle this, I don't know" - haematologist

Long patient contact:
Haematologists are often in a very long term patient-relation and maintain contact with patients for many years. Some even see their patients outside the hospital.

"I have many friends like that, I has many patients who come even to my home, weddings, they come with their children to me. I'm happy that I have done something nice" - haematologist

Frustration:
The relapse generates an emotional and professional frustration, as the given treatment has not worked and the patients are back to shock. When the relapse occurs, there are usually two scenarios; trying a new treatment or palliation.

"This is a desperate situation, because you have done everything you can, but it's not working. It's frustrating. You're disappointed as you did not do your job properly, but it didn't work" - haematologist

● **Origination**

● **Treatment**

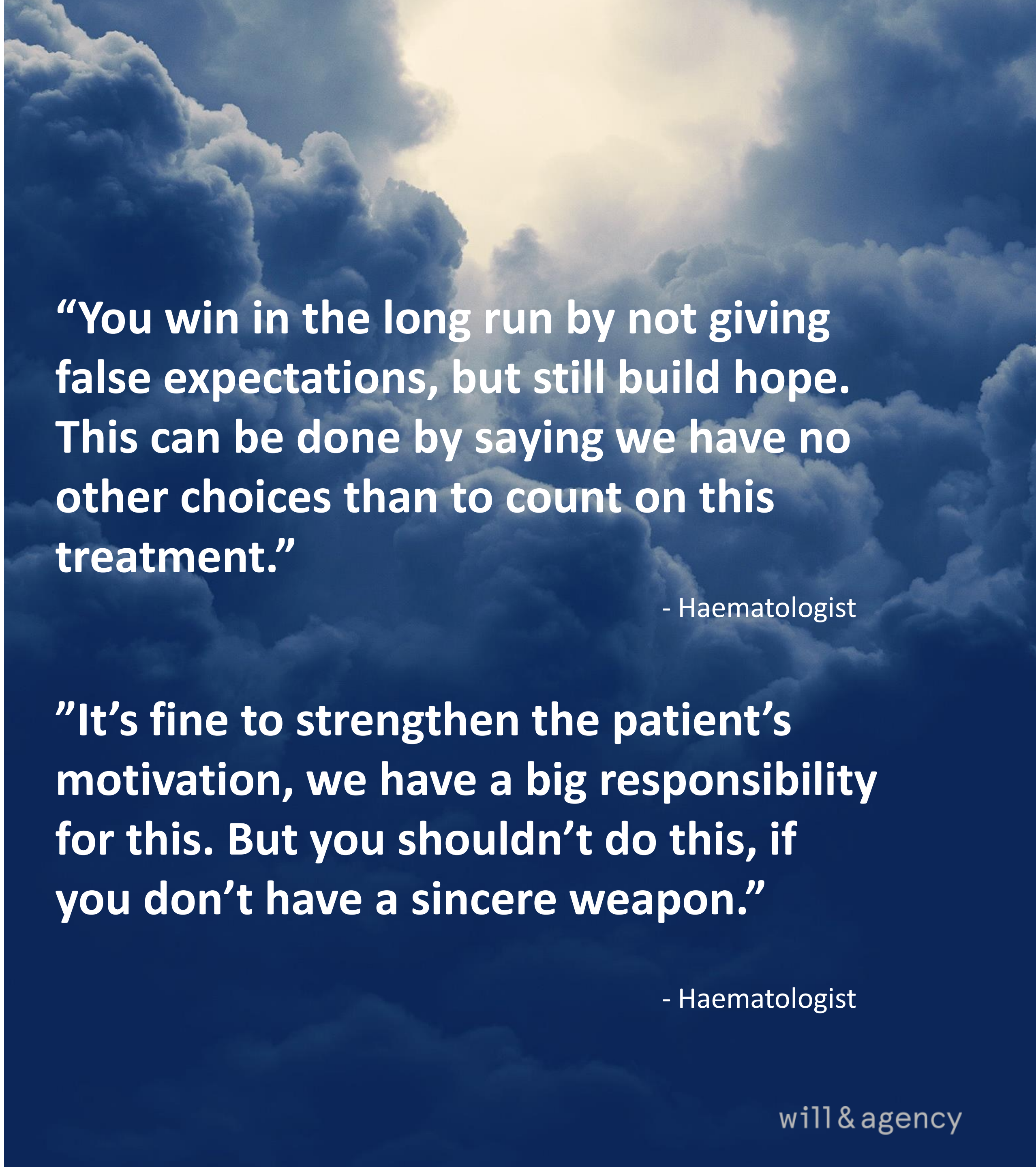
● **Ongoing management**

Hope plays a vital role

The findings from the interviews with six haematologists suggest that haematologists often feel responsible for **infusing hope along their patient's journey both before, during and after treatment.** Many see it as a part of their job description to ensure that the patients are hopeful and motivated, as this is believed to create more positive circumstances for the outcome of the given treatment. This has to do with long patient-relations within the field of AML.

Both patients and significant others acknowledge that **HCPs hold an important role in driving hope** throughout the different steps in the treatment,

However, some also point to a high awareness that they – as health care professionals – cannot and shall not infuse false hope which can create false expectations to the future outcome for the patient. Searching for the right balance was mentioned amongst many haematologists.

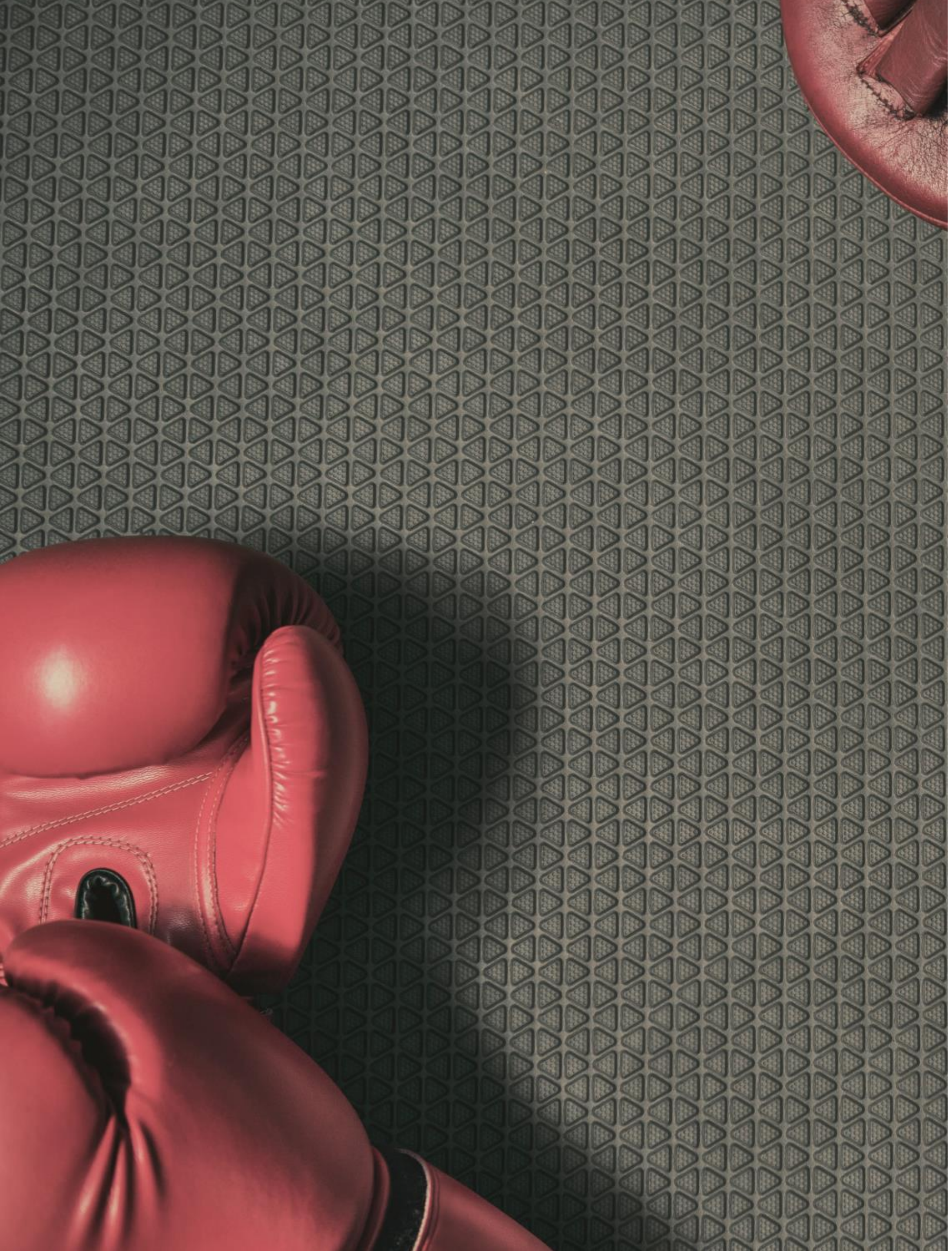


"You win in the long run by not giving false expectations, but still build hope. This can be done by saying we have no other choices than to count on this treatment."

- Haematologist

"It's fine to strengthen the patient's motivation, we have a big responsibility for this. But you shouldn't do this, if you don't have a sincere weapon."

- Haematologist



THE HCPS AND THE PATIENTS ARE IN IT TOGETHER:

”There are patients who want to fight until the end. Even though they can barely walk, they want to try again – and that’s where it gets hard, because that’s where I start to become a little blind, because it’s my patient and I WANT to fight with him.”

- Haematologist

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The HCPs are curious to learn more about their patients

Haematologists and nurses working with AML express passion about their field of work. **They are scientifically driven** by a curiosity of new research and treatments within the field of haematology. **They are motivated to stay updated** and spend their spare time reading scientific journals, attending meetings in different AML groups and going to conferences, when possible.

The HCPs participating in this research point to an interest in a more holistic approach in their meeting with their patients and a curiosity to obtain a better understanding of their patients' lives outside the hospital to use as part of their role as a driver of hope inside the hospital.

However, the findings also suggest that there are **limitations in the holistic understanding of the patient.** The HCPs are very much in tune with the patients when they are in the hospital, but do not always know so much about the patients' lived life outside the hospital; the social consequences of being diagnosed with AML, the physical and isolating consequences of living with AML.

"There was this one patient. She had drawn white dots all over the page, and there in the middle there was one blue dot illustrating her meeting with the doctor. The other dots illustrated her life outside the hospital. That was very important to me, because we think we are so important, but for the patient we're just one part."

- Haematologist

THEY ARE CURIOUS TO CLOSE THE KNOWLEDGE GAP BETWEEN THE HOSPITAL AND THE LIVED LIFE:

“In the hospital we understand and do the practical things, but we cannot imagine everything. I would like to know more about the patient. About the social life of the disease. About what’s going on when the patients leave the hospital.”

- Haematologist

Communication is key – especially for the patients.

The interviews with HCPs suggest that **haematologists and nurses prioritize honesty and being as open as possible when communicating with their patients**. The honesty is seen as a way of **building intimacy and trust** in a treatment alliance with the patient as many find it important for a good treatment. Communication is key, but sometimes **communication takes time and there is a discrepancy** between the communication structure within the hospital system and how the patients take in information.

The patients often cannot remember anything from the first consultations, where the HCPs often deliver the most vital information on diagnosis, treatment and procedures.

For many of the HCPs words like 'trust', 'honesty', 'being open' resonate with how they inform their patients. These words also resonate with how the patients perceive of their HCPs.

"It was a shock for me to get the diagnosis. I was in chock for quite some time. There are many things from that period that I can't remember."

– female patient

"We usually spend half an hour talking to them on the first day, where they hear absolutely nothing. They are in shock, so the first conversation with them is redundant, because it doesn't reach them. But after the first treatment you can say two new things every day, so they slowly can create an image."

- Haematologist

AND THE DIAGNOSIS DICTATES HONESTY, AS YOU CAN NEVER BE CERTAIN OF THE OUTCOME:

“It’s like Russian roulette. Sometimes you get the bullet and it’s bad. But the patients understand. I’m straight, I’m honest to people, I think that’s the best thing in my area, in haematology.”

- Haematologist

will & agency

Coping has become part of the HCPs everyday practice

TO SURVIVE WORKING IN AN EMOTIONAL FIELD, HCPS HAVE TO BE CAREFUL:

“I have to be emotionally detached in some situations, but that’s part of the training. You train to be like cold in your brain.”

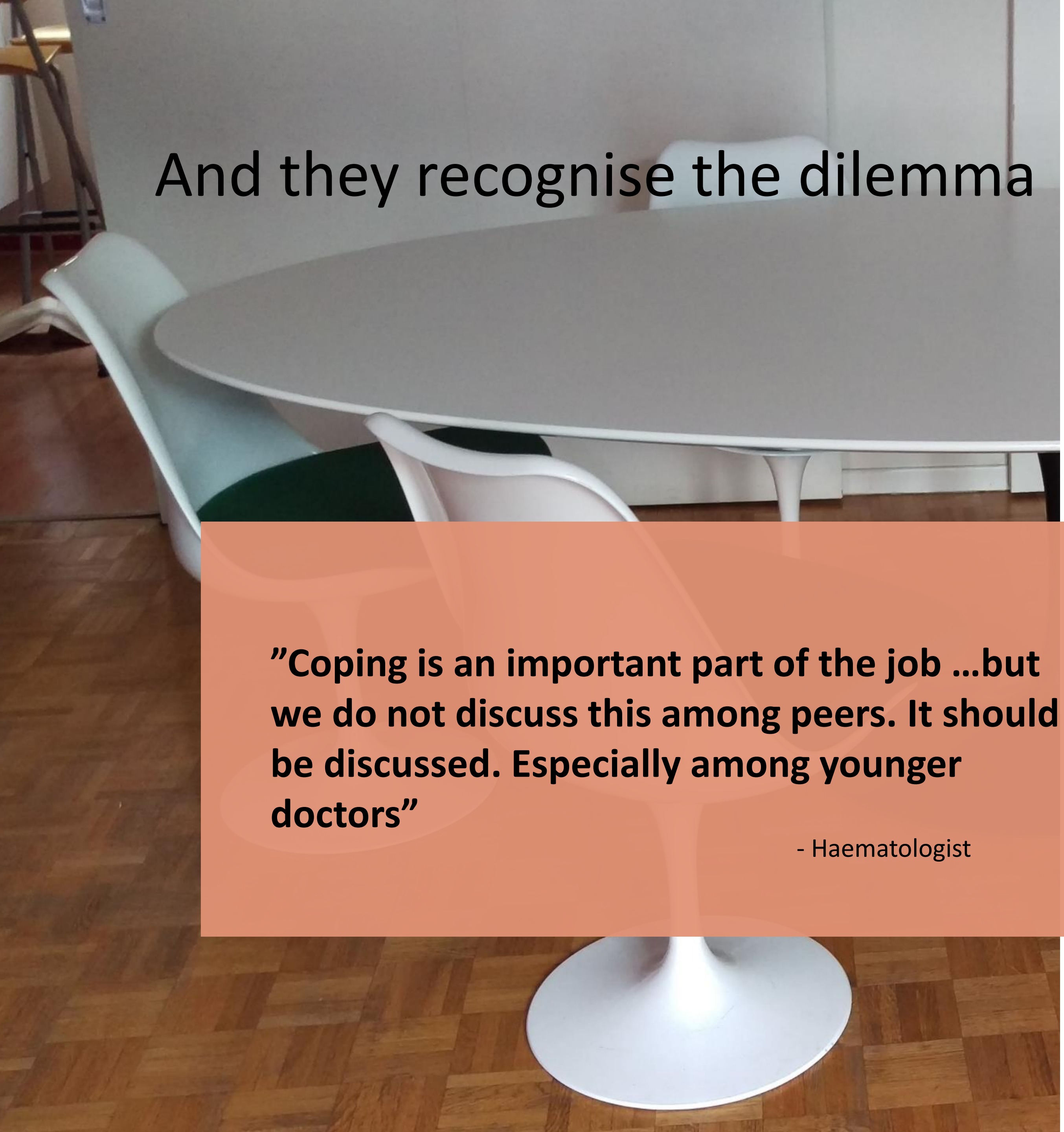
- Haematologist

BUT COPING CAN UNFOLD IN MANY SCENARIOS:

”My colleague - I know she goes out to buy new shoes. Shopping solves frustration. I can’t buy cars everyday.”

- Haematologist

And they recognise the dilemma



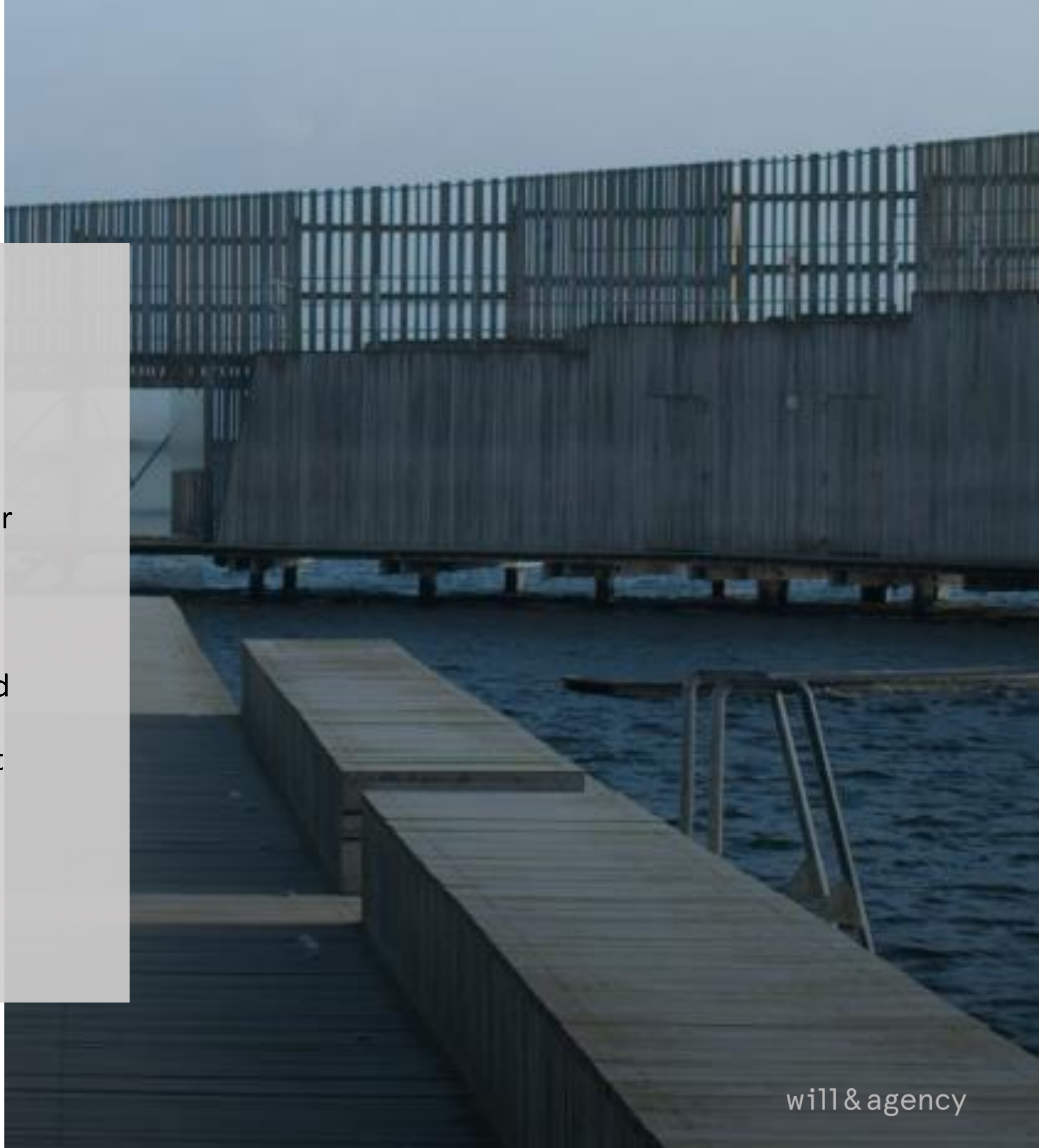
”Coping is an important part of the job …but we do not discuss this among peers. It should be discussed. Especially among younger doctors”

- Haematologist

The HCPs understand that the right way of coping and **ensuring the right balance between emotions (hope) and rationality (facts) plays a vital role** in the actual treatment – but very few discuss the personal coping mechanisms in a broader forum. And here lies the dilemma; they believe it should be addressed as something important (especially for younger HCPs) but it’s a subject matter that rarely is part of their many dialogues, discussions and forums.

Conclusion

Conclusive insights



Based on the interviews with the participants in the research, we have mapped experiences and identified unmet needs from the perspective of patients, significant others and HCPs working within the field of AML. Based on the insights, four key points have been identified and transformed into areas for future initiatives.

Knowing and understanding the life-worlds of the parties involved in the research within the field of AML, the insights presented in this report should be translated into tangible and valuable interventions and initiatives that can support the patients and meet their unmet needs and thus better support the patients throughout treatment and when they leave the hospital.

Recommendations for future initiatives

1

How to hope:

An important learning from the research is that hope is a vital player. Patients, significant others, nurses and haematologists hope and the hope is infused by themselves and others and is maintained socially.

However, hope is closely related to coping and finding the right balance in information, and we need to explore further the origination of hope and understand better how and when hope takes place.

2

Information is key:

All the participants are interested in learning more about AML.

The patients are asking for a more patient-targeted information on AML (and for some patients also information on other patients). The significant others are asking for initiatives directed towards them on how to cope with their experiences and the HCPs are curious to close the knowledge gap between learnings from inside and outside the hospital.

3

Isolation should be mitigated:

Isolation is by far the biggest unmet need which have been identified in the research. Both patients and significant others touch upon this as something that affects their everyday life (and quality of life).

An intervention aimed to mitigate the feelings of isolation is aimed to assist and support patients and significant others through the treatment and to help them adjust to life with AML.

4

A separate focus on the significant other:

Helping significant others cope with the treatment process is an important unmet need which has been identified.

The significant others are under a large amount of pressure and often have to act as the eyes and ears of the patient during the treatment process. They often tell the story of the patient and stand in the background while playing a vital role in the patient journey. The significant others need more support and guidance throughout the process as the Swedish health care system can not fully provide the support they need.

Astellas Pharma

Tel: +45 43430355
Fax: +45 43432224
Email: kontakt.dk@astellas.com
Website: www.astellas.com/dk