



InSites Consulting

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# Heart Matters: ATTR-CM community

Creating patient-centric support programs by  
collaborating with patients and caregivers

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## Background

In April 2020, Pfizer Australia contracted InSites Consulting to conduct research with patients living with Amyloid Transthyretin Cardiomyopathy (ATTR-CM) and their carers.

The research methodology is designed to provide a safe environment for individuals to share stories, perspectives and insights into their experiences to identify similar trends, which Pfizer can use to help develop support programs for both patients and carers.

The quotes shared are individuals' perspectives, which Pfizer has not edited in any way. InSites Consulting assessed the insights collated from the research to summarise the findings and identify common themes to help Pfizer focus on support programs in the future.



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**JOURNEY TO DIAGNOSIS**

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**SUMMARY & RECOMMENDATIONS**

# Overview of Approach

## QUALITATIVE COMMUNITY SQUARE

Online community, consumer journey immersion  
2 week deep dive

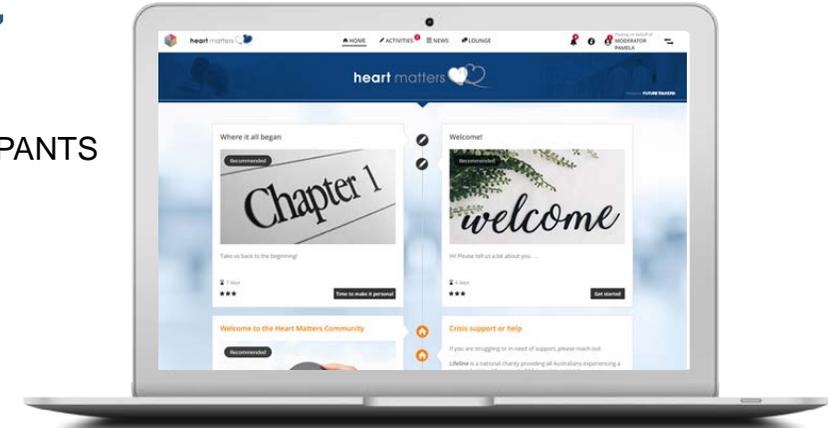
*Fieldwork: 30 April - 22 May 2020*

## RESEARCH FLOW

- *Welcome*  
Warm up and introduction, lifestyle
- *Where it all began*  
Contextual understanding of history with ATTR-CM from initial symptoms to today
- *Your personal journey*  
Understanding major events, emotions and information sources along health journey
- *A picture paints a thousand words*  
Key tensions, challenges and emotional landscape
- *A day in your shoes*  
Impact of ATTR-CM on daily life
- *Experiences with healthcare professionals*  
Identify any gaps in patient needs
- *Write a letter (patients/carers)*  
Understand what they would like patients, family and friends to know
- *A message to others*  
Understand what they would like the wider community, media, government to learn
- *Current support and information*  
Explore current information and support services used, and the role they play
- *What's missing?*  
Understand gaps in support or information needs of patients and carers, and how would an ideal support program look
- *Time to share your feedback*  
Patient/Carer feedback on non-branded/disease awareness materials & channels for delivery (e.g. SMS, email, pamphlet, online, etc)

## WHO WE SPOKE TO

**10** **7**  
DAYS PARTICIPANTS  
**75**  
POSTS



## Australian patients diagnosed with ATTR-CM or primary caregivers

|         |                    |                   |                     |                    |                 |                   |
|---------|--------------------|-------------------|---------------------|--------------------|-----------------|-------------------|
|         |                    |                   |                     |                    |                 |                   |
| Patient | F, 30-34, hATTR-CM | M, 55-59 hATTR-CM | M, 70-74 wt/ATTR-CM | M, 70-74, hATTR-CM | M, >75 hATTR-CM | M, 60-64 hATTR-CM |
| Carer   | no                 | no                | spouse              | spouse             | spouse          | F, 60-64 (spouse) |

wt = wild type 5  
h = hereditary



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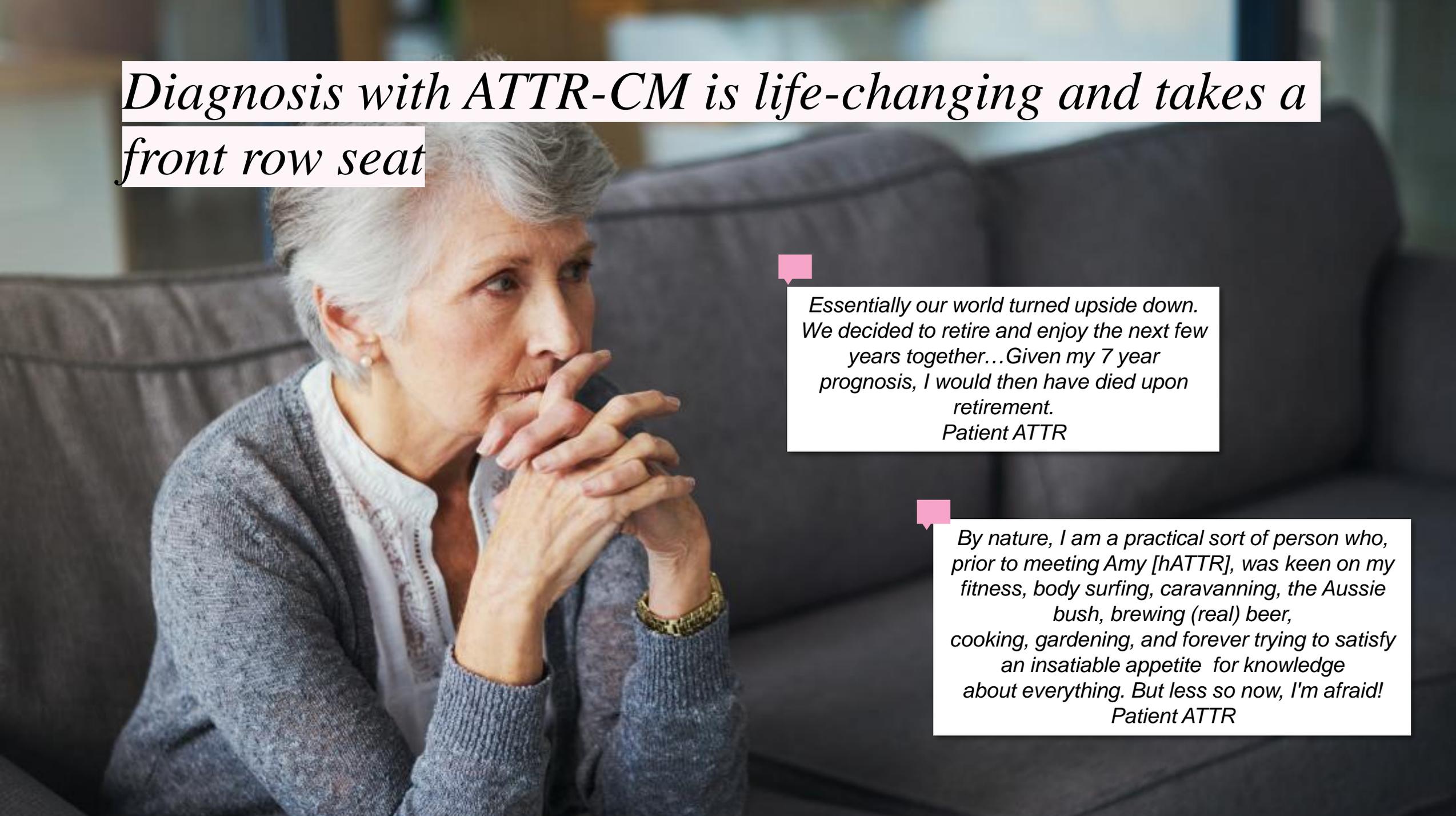
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*Diagnosis with ATTR-CM is life-changing and takes a front row seat*

*Essentially our world turned upside down. We decided to retire and enjoy the next few years together... Given my 7 year prognosis, I would then have died upon retirement.*  
Patient ATTR

*By nature, I am a practical sort of person who, prior to meeting Amy [hATTR], was keen on my fitness, body surfing, caravanning, the Aussie bush, brewing (real) beer, cooking, gardening, and forever trying to satisfy an insatiable appetite for knowledge about everything. But less so now, I'm afraid!*  
Patient ATTR

# Diagnosed patients (and carers) often make major lifestyle changes as they face new sources of stress/anxiety

## Shift in life priorities

- **Retire early** to do what they always wanted to do, e.g. travel
- Seeking **new experiences**, adventures, tick off the bucket list
- **In a hurry** to fit in as much as they can before they can't
- Visiting family more often

*We made a conscious decision to die living rather than live dying and make the best of each day.*  
Patient ATTR

## New fears

- **Passing on the gene** to offspring
- **Increasingly dependent** while health deteriorates, impacting on the quality of life of spouse and family
- Leaving loved ones behind
- Know it is **incurable**, always in the back of their mind

*I'm 33 and had my genetic testing when I was 20 that confirmed I had the gene for hereditary familial amyloidosis. I have 2 beautiful girls who I had tested in vitro at 12 weeks gestation, who thankfully do not carry the gene.*  
Patient ATTR

*One great fear is that our nieces and other cousins may get this disease. Whilst our kids are negative, one from hospital gene test, two got me to read their 23andme data. Whilst Drs ok'd my results cautiously, I fear they could be wrong. **Our niece is awaiting her gene tests - flip of the tummy every time I think about this.***

Carer ATTR

## Financial strains

- **Forced early retirement** putting a dent in financial plans, sacrificing dreams, loss of income
- **Ongoing medical cost** burden
- Some concerns that if effective medication becomes available, that affordability could be an issue
- Challenges seeking financial aid

*We are living on our ever dwindling Super, if [patient] qualified for disability support it would help us cope financially. **Centrelink told us to come back when he had a year to live. That night we both said it'd be OK to go to sleep and not wake up.***

Carer ATTR

# Living with ATTR-CM is full of uncertainty, except for the certainty of slow deteriorating health



## Daily frustrations

- Unexplained fatigue/lethargy
- Shortness of breath
- Mobility issues related to neuropathy
- Constant medical appointments and related travel requirements

Life revolves around work, my kids and 6 monthly visits to the hospital for my appointments and tests.  
Patient ATTR

## Uncertainty

- Not knowing what the future holds, how the disease will progress or how quickly
- Not knowing which stage they are on the path
- Feeling out of control, helpless

Not knowing. Not knowing where I am on the path. **Not knowing how things will pan out.**  
Patient ATTR

[We found last May] the **disease can manifest differently in each person, even siblings may be different.**  
Carer ATTR

## Being hypervigilant

- Every new sensation or change may be a sign of deteriorating health
- High sensitivity to anything that changes in their body
- Self-doubt, concerned about being seen as paranoid / hypochondriacs

Happened this week. As I was washing my hands it felt like I had a hair on my finger that I could not see and not shake off. Once, not a problem. Twice, strange. Nearly every time, I washed my hands. Always the same finger, same place? What do you think? **Me being stupid, or a part of the progression?**  
Patient ATTR

## Slow and quiet degeneration

- Anxiety over not being able to recognise all signs
- Expect a slow degeneration towards immobility
- Especially pronounced fear/anxiety if they have witnessed a relative deteriorating in health over their lifetime

**A nasty quiet disease that creeps up on you.** when you suddenly realise that what was an annoyance is the next stage in your journey and it shocks you that it has been there so long  
Patient ATTR



## *Some have been living with clues for ATTR-CM diagnosis throughout their lives...*



Prior to experiencing symptoms themselves, some patients observe **one or several family members'** health deteriorate slowly over years/decades



'**Casual mentions**' of '**amyloidosis**' by doctors in personal (or relative's) medical records remain as notes without follow up investigation until patient becomes symptomatic



*Single mention: Disease prognosis is perceived by patient/carer to play out in very different ways, so close family members may not be a good indicator of their pathway*



*I grew up my whole life losing family members. I was 7 when we lost my **Uncle** just 34 years old, I don't remember a time where he wasn't sick. Then my **Aunties** both got sick and we moved to Australia for a year so they could both have transplants. One Auntie died roughly 6 months after her transplant and another a few years later. Then my **Mum** started getting sick and the signs all pointed to the same thing my aunties and uncle died of. So after a couple years of her being sick I had decided I needed the genetic testing I wasn't going to wait around and let this thing blind side me I wanted to get ahead of it if I could.*

*Patient ATTR*



*In the autumn of 1985, just after I turned 21, my father died. He had been ill for a long time, but it seemed no one knew why. While I was in my late teens/early 20's, I watched him slowly deteriorate, something that took 5 years, until he could not walk the 5 steps to the bathroom, unable to get up and down stairs, so he lived in the living room sofa. When he died we were told it was Congestive Heart Failure and, **while 'Amyloids' was mentioned it seemed that none of the doctors really knew about it.***

*I know what is to come, I have seen it, heard it, and felt it.*

*Patient ATTR*



*So back to the neurologist and a myriad of inconclusive tests followed. However, a breakthrough came when the neurologist was poring over an earlier hospital report from my admission to Cardiology for uncharacteristically passing out, and found a **casual reference to Amyloidosis???** A sural nerve biopsy followed in February 2012, and it confirmed Amyloidosis.*

*Patient ATTR*

# *Uncertainty over prognosis draws energy and focus on meeting current daily needs, and less on future planning*

If carers are in the picture, they often carry the burden of planning for the future





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An elderly couple is walking through a field of tall, golden-brown grass. The man, on the right, has white hair and is wearing glasses and a dark blue t-shirt. He has his arm around the woman's shoulder. The woman, on the left, has short blonde hair and is wearing glasses and a white short-sleeved shirt. They are both smiling and looking towards the camera. The background shows a line of trees under a bright sky.

## *A long and convoluted road to diagnosis*

*"We know of one heart specialist who told his patient when queried about possible amyloidosis: "That's too exotic for you to have." He died soon after.  
Patient ATTR*

# *A need to raise awareness of hidden or missed clues to guide towards earlier diagnosis*



## Hidden

- **Low awareness** of the condition (general public and GPs)
- Many experienced **little to no symptoms**
- **Excused/ignored** mild symptoms (e.g. reaction to preservatives in wine, poor sleep)

*I remember reading about **one doctor who said they first time they heard about it was in an episode of House** - I saw that one too, my wife and I beat him to the diagnosis that time.  
Patient hATTR*



## Under-diagnosed or misdiagnosed

- Often **disguised or masked** by other health conditions, e.g. atrial fibrillation, carpal tunnel
- Few indicated investigations were conducted to rule out other health issues after one diagnosis

*Before diagnosis, they [**doctors**] need to listen a little more. The signs are small but can be seen, don't put us off and don't stop looking during and after diagnosis.  
Patient hATTR*



## Dismissed

- Some felt that **GPs ignored or did not believe them** when patients raised suspicions about their condition based on family history (memory/recall)
- Clues potentially held in family history, but no further investigations occurred

***My GP didn't believe [us]**, we had to say what it was each time, and we found out later he didn't write our records up.  
Carer*



## Long journey

- Lengthy time between first symptoms or signs and diagnosis, **often spanning years/decades**
- **Patients and caregivers become detectives** and researchers in connecting the dots between their diagnosed conditions, tests, and across different HCPs

***My journey [has been] from age 21 to today, 56**, and until recently was more my teaching, not being taught or helped with my (at the time) potential health problem.  
Patient*

# *Path to diagnosis for asymptomatic and symptomatic patients differ*

## **Asymptomatic**

*"My partner and I had sent to a company in the USA saliva to do some **genetic testing to trace our heritage in 2010**. On one report, it said I had the gene for hATTR. At the same time, my brother finally got his diagnosis after trying to find out what was wrong for years. This gave me the information to have a heart biopsy procedure. The results came back positive with amyloid found in my heart wall. So I had hATTR with Cardiomyopathy 60 ala type. At the time of diagnosis (2014) this created great anxiety as I could see the path my brother was on, and I expected to follow him."*

*Patient ATTR*

## **Symptomatic**

*"In my late teens/early 20's **I watched my father deteriorate until he could not walk 5 steps** to the bathroom. When he died we were told it was Congestive Heart Failure and, **while Amyloids was mentioned it seemed that none of the doctors really knew.***

*Fast forward 30 years and I am diagnosed with Carpal tunnel in both wrists. It felt the same as my father described, so while I was waiting for surgery, I investigated Amyloids and found the team in Westmead. They agreed to me being tested and they took the bloods etc. after the surgery the surgeon also tested one of the samples from my wrist. I had the diagnosis confirmed from both sides."*

*Patient ATTR*

## TRIGGER TO SEEK ADVICE

### Trigger

- **Symptomatic (first/new symptoms)** prompting GP visit (e.g. tingling toes, continuous 'pinched nerve' sensation, difficulty with grip, mis-stepping, burning shooting pains, breathlessness, tiredness, tremors in hands, strange upper body and arm sensations, passing out...)
- **Asymptomatic** but observed one or several close family members experiencing unknown chronic illness (e.g. heart conditions), or reading casual reference to amyloidosis in deceased parent's medical record

## INFORMATION SEEKING

### Research

- **Initial broad** search for information to understand general diagnosis, symptoms, treatments, prognosis...

## DIAGNOSIS

### Final diagnosis

- **ATTR-CM (wt/h)**

### Initial diagnosis

- **Atrial Fibrillation**
- **Carpal tunnel syndrome**
- **Neuropathy**
- **Genetic results** indicating gene for "hemochromatosis and Familial Amyloidosis Polyneuropathy with Cardiomyopathy aATTR60" Patient ATTR

### Inconclusive

## TESTING

### Medically advised tests

- **Medical tests** e.g. angiogram, blood tests, MRI, cardiac biopsy, nerve conduction study, sural nerve biopsy...

### Patient initiated tests

- **Commercial genealogy / heritage tests**, e.g. 23andme

## TREATMENT

### Treatment

- **Surgery** for carpal tunnel in wrists
- **Medications** to manage various symptoms

## INFORMATION SEEKING & SHARING

### Awareness

- **Talk to GPs/other HCPs** often raising awareness
- **Talk to family/friends** to explain the condition and to make plans for the future
- **Join online (social media) groups** seeking support and more specific information from other patients
- **Mostly carers:** actively research publications, involvement in advocacy groups

# In their words and images...

the **shock of finding out** was like a **bull in a china shop**, added writer that our children might have it (they don't).



The questions and answers. The whole journey is one **long series of questions with few answers**.



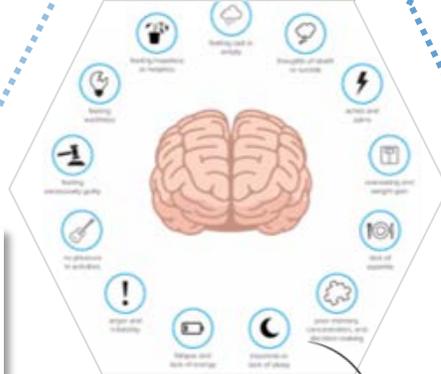
The majority of the time my main emotion is similar to being in a state of **confusion**. too much or too little or not being able to process the information.



The Sydney Harbour Bridge showing through the fog shows the way I feel, **lost unable to see whether i am going or coming**. Hopefully there is a bridge to help me.



The roller coaster is a good example. the **highs of finding something followed by the crash of it being a dead end**, all the while going around and around on something that **feels very unstable**.



Sometimes **overwhelmed and depressed**, trying to keep up with research on understanding the disease. Are trials becoming available-who decides.



it has all been hard and hurts but when you stop, because you have found it can be done, then **the pain can go away**.

the calm seas and **acceptance**. The sea may change and become rough with little or no warning and the acceptance, this is what I am still aiming for, although it will be hard.





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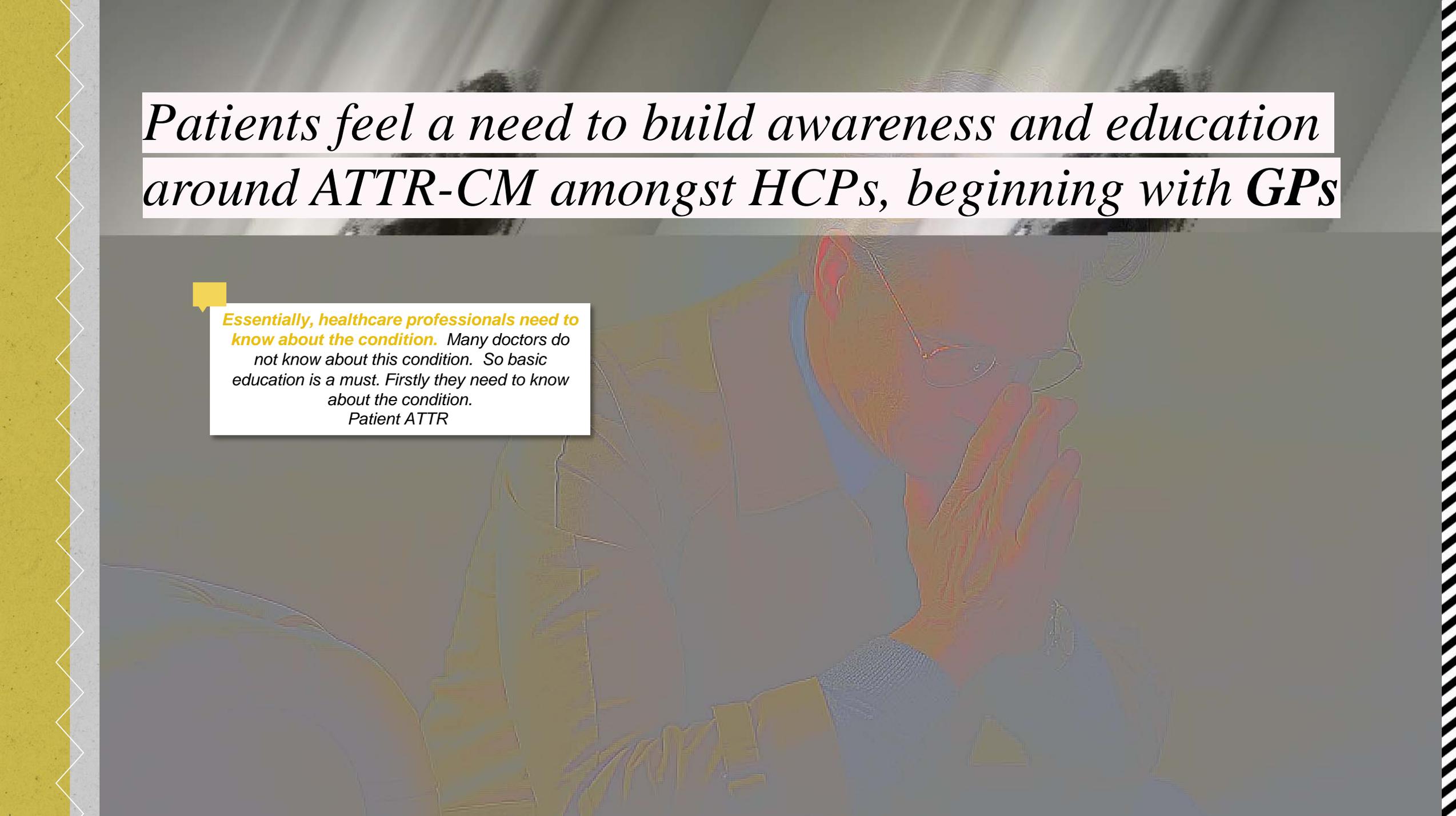
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*Patients feel a need to build awareness and education around ATTR-CM amongst HCPs, beginning with **GPs***

**Essentially, healthcare professionals need to know about the condition.** Many doctors do not know about this condition. So basic education is a must. Firstly they need to know about the condition.  
Patient ATTR

# *GPs appear to be the first roadblock to diagnosis due to lack of awareness and knowledge*

Patients presenting with seemingly minor/mild symptoms, or clues of family history of ATTR-CM often feel ignored or dismissed by GPs

## First clues / symptoms as described in patient's words...

- Shortness of breath / breathlessness
- Tremors in hands
- Tingling toes/fingers
- Tiredness
- Strange upper body & arm sensations
- Difficulty with gripping
- Mis-stepping
- Continuous 'pinched nerve' sensation
- Burning shooting pains
- Passing out

*A GP didn't believe us, we had to say what it was each time, and we found out later he didn't write our records up.*

*Carer ATTR*

*Ideally, it starts with the GP. They are the catcher, they would be able to **drill down to the initial diagnosis faster than now.***

*Patient ATTR*

*...they [HCPs] need to listen a little more. The signs are small but can be seen, don't put us off and don't stop looking.*

*Patient ATTR*

*Finding out [he] has this gene wasn't too worrying as he said he didn't have any symptoms, even though he did we later realised. **Luckily his GP had once dealt with this disease when he was an Intern.***

*Carer ATTR*

*Misconceptions start with the medical profession. It's [been] a long journey for us all. Given this disease can be masked by other possible conditions it is recognised to be **difficult.** And we can't expect doctors to know everything.*

*Patient ATTR*

# Patients and GPs tend to play reversed roles; patients become the experts



## Patient often do their own RESEARCH

- Due to a lack of GP awareness and knowledge, patients often conduct their own research, leading to diagnosis
- Patients tend to remain more up-to-date with medication innovation / trials than GPs

*Until recently, I seemed to be telling them about something they had never heard of. So they could not really support my search for information. I had to do my own research, what was happening, where and was it possibly any use to me.  
Patient ATTR*



## GPs don't often have any ANSWERS

- Patients hope GPs will gain further knowledge about ATTR-CM in future
- As a starting point, they expect a degree of attention to minor (and persistent) symptoms, as well as further investigation of their family health history

*I totally agree with comments on **education and talking and listening to the patient, and their family**. Yes, they [GPs] do not have all the answers (yet), but each person they listen to helps to improve the knowledge base.  
Patient ATTR*



## Patient leads path to DIAGNOSIS

- Patients often proactively present their hypotheses and push for further investigation

*Primary health care workers & medical specialist/s in their area of expertise - **It can be hard finding ones that are suited [as a source of support/information], but once that happens then its great.**  
Carer ATTR*



*Access to the right **Specialists** provides greater patient reassurance in quality of healthcare*

I have the highest regard and trust in. **All the decisions are made including me and each Specialist plays an equal part.** They also keep in contact with my GP and all other doctors I see and again no changes are made until everyone is happy, that includes me each time. **Now the best advice I get is 'what do you think is best'. So for me this says, what you want is what we will head towards.**

Patient ATTR

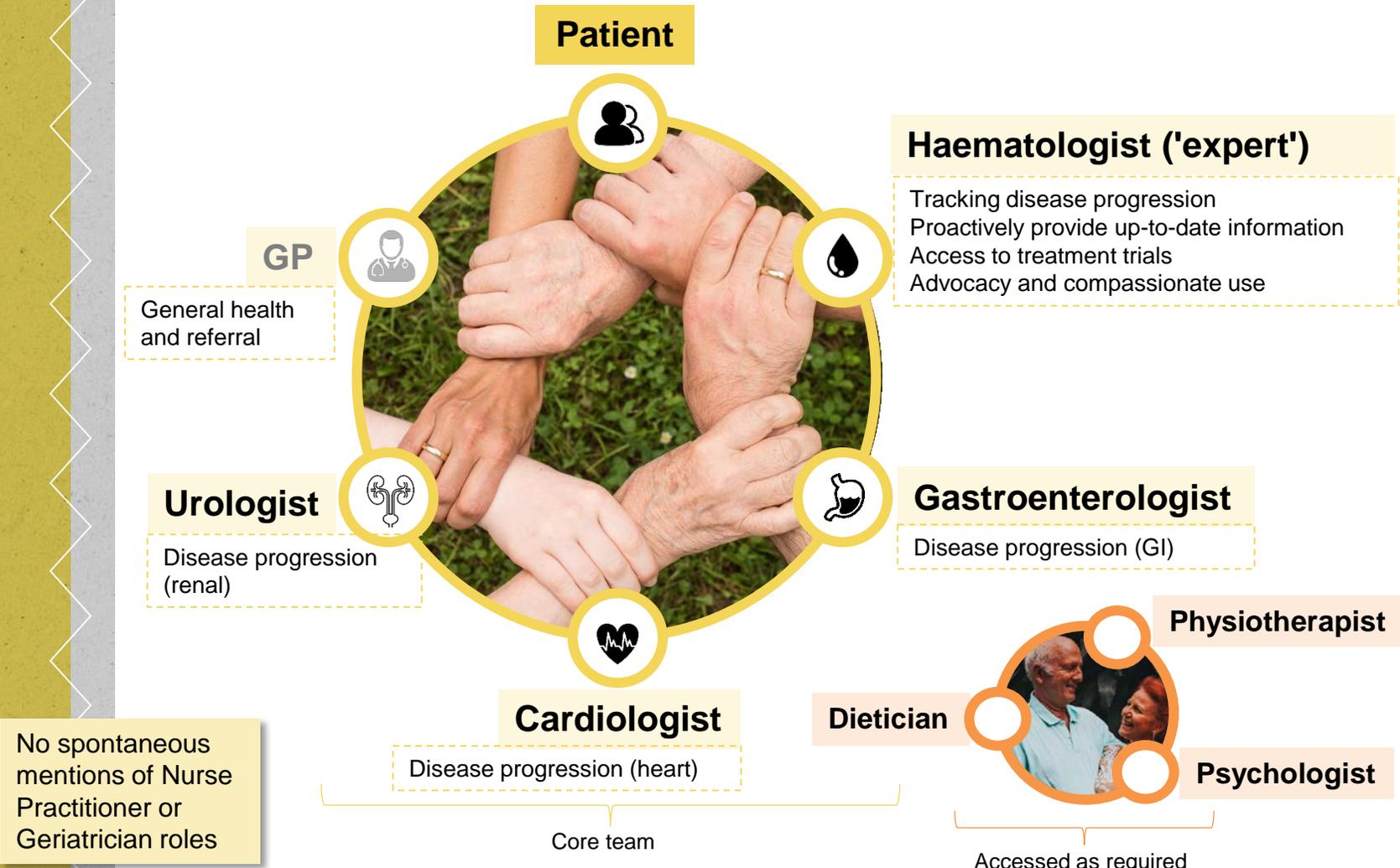
**We don't know what we don't know - please be more proactive in explaining treatment & trials.** Background information [is] the most important, then we can make decisions.

[we need support/information] from the primary health care & medical specialist/s in their area of expertise. **It can be hard finding one/s that is/are suited, but once that happens then its great.**

Carer ATTR

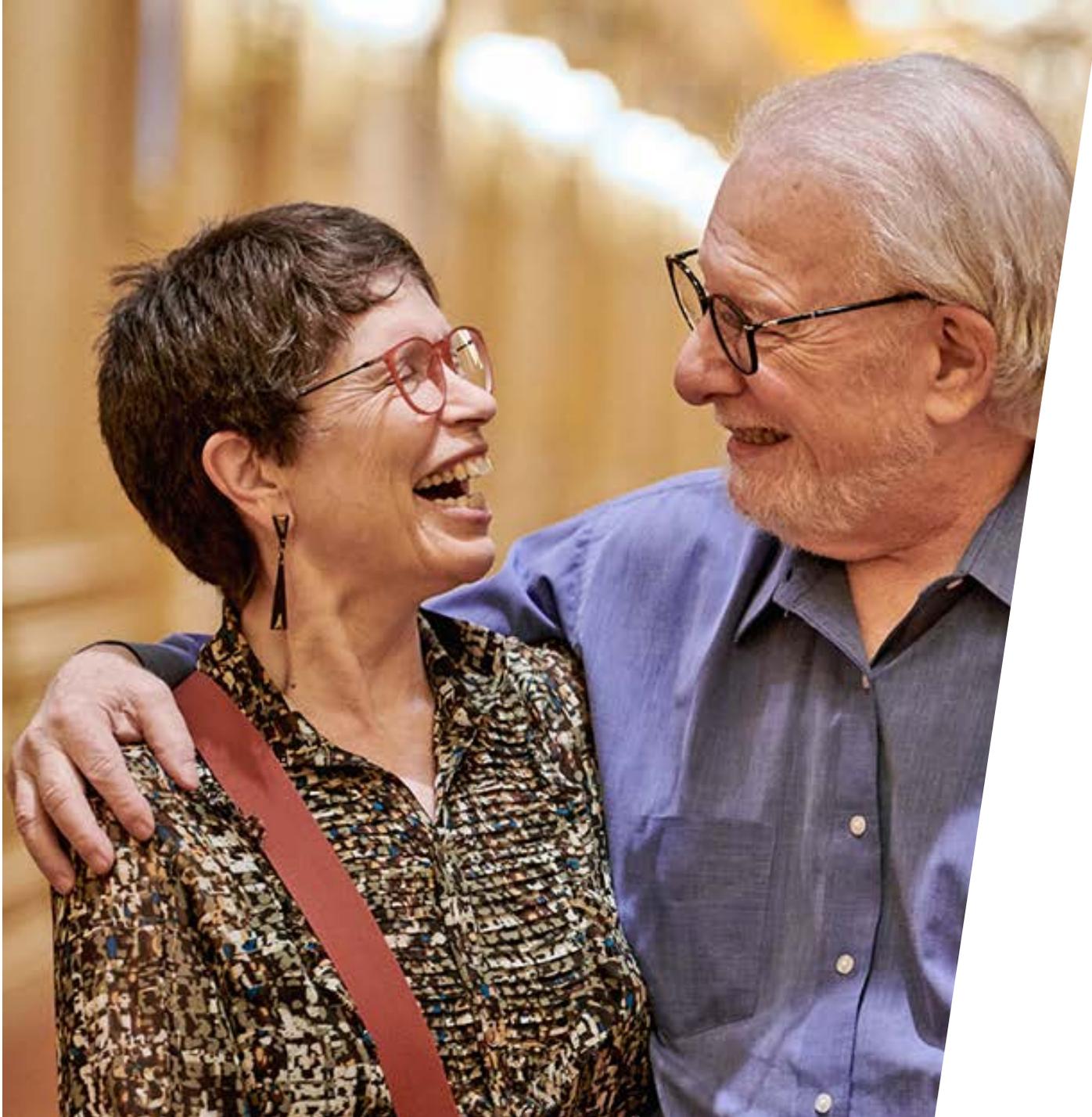
# Overall, positive experiences with multi-disciplinary HCP teams, but opportunity for GPs to play a stronger role upfront

Given lack of HCP awareness and knowledge of ATTR-CM, patients &/or carers currently play a strong role in the healthcare team



*The team's first task is to be introduced to the patient and carer as a group. This would help so that the patient is not being handed from one to another with no continuity... At some point, a team meeting including patient and carer for an update could help some to understand how things are, if they need/want to know.*  
Patient ATTR

*It is helpful having good access to an excellent world class doctor... I get most of my contemporary information from my haematologist who is the best connected and knowledgeable around my condition. Other specialists, while interested, do not have the knowledge that my haematologist has. Different specialists and GP's are learning but it's also process. The information which I have found most useful relates to my treatment, access to medication and trials, and contemporary information.*  
Patient ATTR



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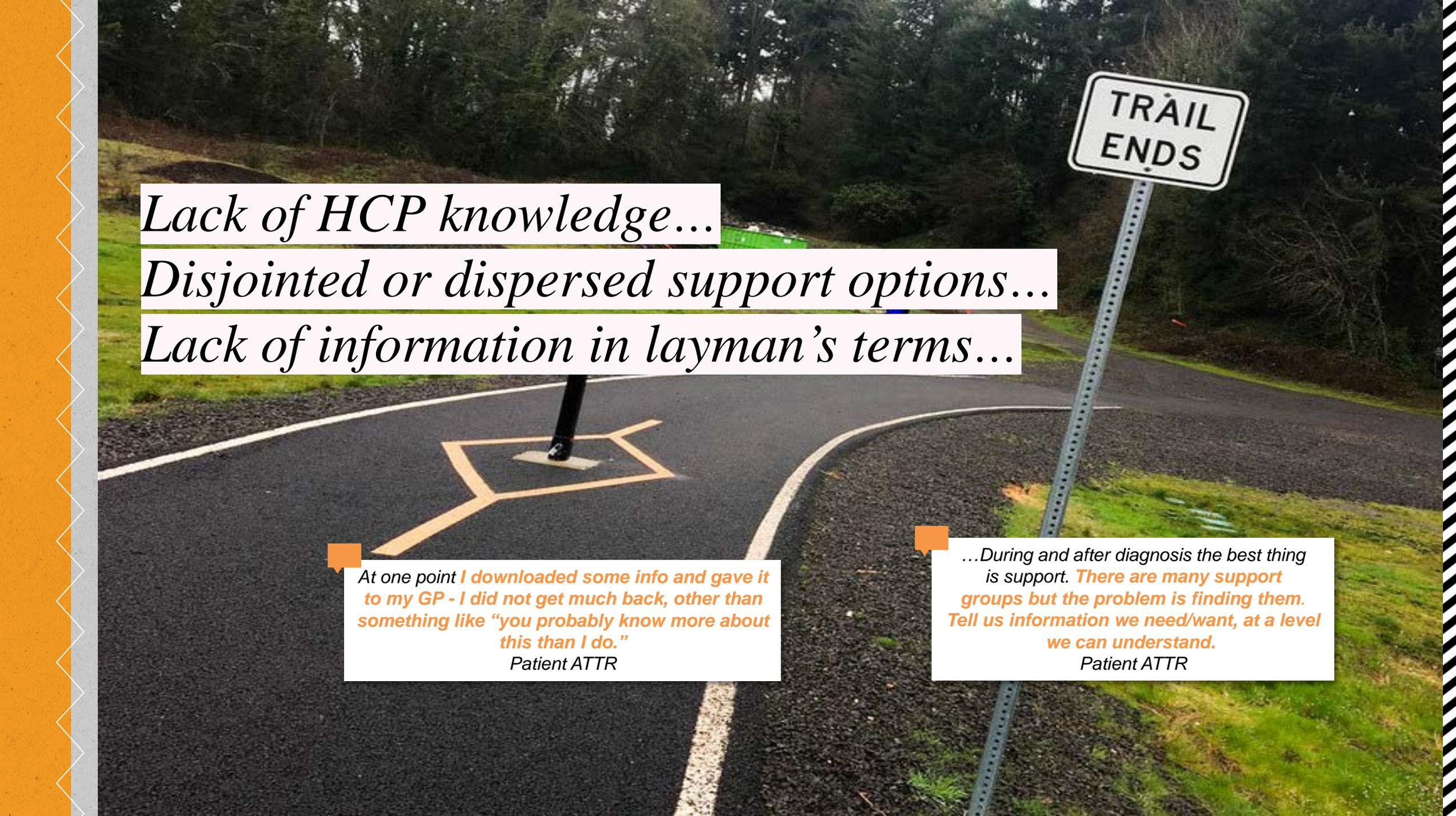
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A paved path with a yellow square on the ground. A sign on a metal post reads "TRAIL ENDS". The path is surrounded by green grass and trees.

*Lack of HCP knowledge...*

*Disjointed or dispersed support options...*

*Lack of information in layman's terms...*

*At one point I downloaded some info and gave it to my GP - I did not get much back, other than something like "you probably know more about this than I do."*

*Patient ATTR*

*...During and after diagnosis the best thing is support. There are many support groups but the problem is finding them. Tell us information we need/want, at a level we can understand.*

*Patient ATTR*

# *Psychological support for both patients and carers is felt to be missing*

**Difficulty FINDING support networks**

*Personally I feel the main thing missing in support network is psychological help right at the start for both patients and care givers. It is such a big thing that I feel the whole team that will be there to help needs a source of this type on it. They need to be able to help the patient and carer to start to recognise what is happening and they can help the team understand where the patient is in terms of where they are mentally and able to understand and take in how things change over time. Patient ATTR*

**Most rely on informal (social media) support groups**

*Friends and Family - emotional and social support - often can't burden them with too much. FB patient group/s - lovely to know we're not alone... Support group/s - often the best info as they look into it for you and can offer more links, social get-togethers and information educational forums. Carer ATTR*

**Little perceived CARER support available**

*There needs to be far more support for carers and carer support networks. This condition is often fatal and certainly has major psychological repercussions on carers. Patient ATTR*



# Carers tend to address different support needs by accessing multiple organisations

**THE GAP:** a dedicated nation-wide patient advocacy group to provide both patient and carer support - *representation, education, up-to-date information, and connection with other ATTR-CM patients.* Additionally, there is hope for more *globally aligned* collaborations / partnerships.

## Australian Amyloidosis Network

- Advocacy
- Education, credible information & access to trials
- BUT patients/carers would like a patient sub-group for regular patient-led dialogue

## Leukaemia Foundation

- Advocacy and some support
- BUT amyloidosis is not their core

## Rare Voices Australia

- Advocacy and support

## Facebook groups

- Peer / social support
- Share information links
- BUT patients are cautious about credibility of information shared here

## Amyloidosis Alliance

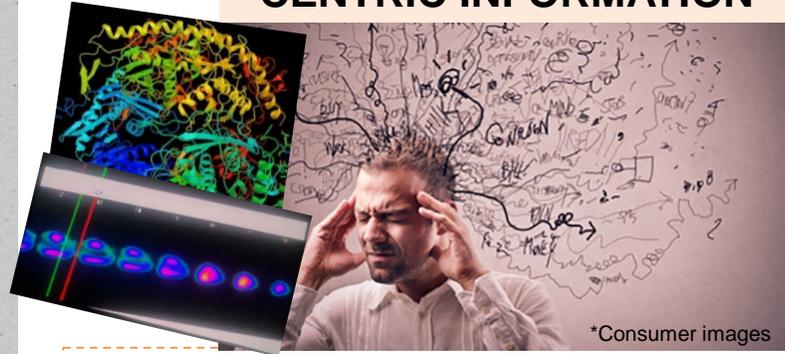
- Up-to-date information
- Support on a global level



*Limited mentions: Currently, ATTR-CM patients/carers are not opposed to pharmaceutical sponsorship, as long as their support needs are met.*

# Current perceived scarcity of patient/carer-centric information leaves people either paralysed or exhausted by being in constant search mode

## LACK OF PATIENT-CENTRIC INFORMATION



At the beginning, patients lack understanding of their diagnosis  
....and even less seems to be known about their prognosis

Patients and carers

*I don't like not being in control of what happens and hate not knowing the what and why of things. **There are what seems like a million ways I can go, so my control is little to none.***

*Patient ATTR*

## CONSTANT SEARCH FOR INFORMATION



Finding any information, incl. published medical or scientific papers, provides some with a sense of control and comfort  
...but this does not always enhance patient or carer understanding

Typically carers

***NCBI [national center for biotechnology information] papers** in the main, and other ethically presented papers - a bit of work but often wonderful information, you have to be careful to hone down what you want and if that paper meets the need...**it can be extremely draining to go through all of them for an answer...***

*Carer ATTR*

# *Although online enables access to information, patients would like more relevant, specific and up-to-date information*



## Seek **BROAD UNDERSTANDING** of their diagnosis

- **Information needs at diagnosis are the strongest**
- Patients feel overwhelmed and need **easy-to-understand info** for themselves and to explain to others
- According to patients, some **GPs admit they know less than their patients**

*Not sure I can give a good answer to this. I am not sure what my current needs are, so **I don't know if I have the right information.***

*Patient ATTR*

*I don't share very intricate papers as they would be **too boring and involved for most people, including me***

*Carer ATTR*



## Seek **SPECIFIC INFORMATION** relevant to living with condition & prognosis

- Seek practical info specific to **daily living needs**, habits to develop to enhance health including nutrition, exercise, etc.
- **Planning for future needs**, e.g. home modifications, aids, end of life, etc.
- While not all patients stay up-to-date with **latest treatments** available, there is hope HCPs will keep them updated, e.g. treatment, medical breakthroughs

***I am now interested in my specifics and most of the information is a general nature...** what sort of things do I look at like where do I live, should I look at other changes in the house or anywhere else now, before it is too late. When is too late?*

*Patient ATTR*

*I use the term contemporary...Essentially its about **ensuring one keeps up to date with information** provided as it is changing all the time. For example there are new varieties of hATTR being found. Also **treatment options and availability** in particular countries will vary across the world and are being rolled out following trials and acceptance by the country's medical system.*

*Patient ATTR*

# Raising awareness of ATTR-CM and early detection is the first step...



## MEDIA

- **Raise awareness** for a condition that has been hidden for too long
- **Help patients recognise their symptoms** to prompt earlier help seeking

**Put the word out so members of the community can look at their own symptoms, perhaps on Amyloidosis Day May 8<sup>th</sup>. For years this condition has been hidden. It's time for it to be revealed.** For too long this disease has taken too many people, all without a proper diagnosis. Those days are now behind us and as a patient living with hATTR-CA, I'm calling on the media to play their role in exposing this cruel condition, which is a killer.  
Patient ATTR



## GOVERNMENT

- **Raise detection rates** beginning with GP awareness/education
- Allow access to **financial support** for patients and carers, e.g. disability support access
- PBS consideration

*The time has come for our political leaders to get out of the trenches and deal with this killer. hATTR-CA has already taken too many lives and the **government now has the information and medical knowledge to deal with it head on.***  
Patient ATTR



## PHARMACEUTICAL INDUSTRY

- Patients are aware research is being conducted, which may allow access to treatments and trials
- Accept that they may not directly benefit from treatments being researched today, but hope that using them as experimental subjects will contribute to enhancing the lives of patients tomorrow

**This condition is a death sentence.** Your research into this hereditary disease is to be commended and your historical approach to searching for a cure is well known. **I appeal to your commitment to humanity and to individuals living with hATTR to make medications available and affordable.**  
Carer ATTR



## PATIENT ADVOCACY

- Provide a voice to ATTR-CM patients, who have different needs to other patients
- Currently being referred to support organisations / groups where their needs are different

*All these groups do some good on their own, but two or three working together can influence the others into action.*  
Patient ATTR

**EXECUTIVE SUMMARY**

**BACKGROUND & APPROACH**

**LIVING WITH ATTR-CM**

**JOURNEY TO DIAGNOSIS**

**HEALTHCARE PROFESSIONALS**

**SUPPORT & INFORMATION NEEDS**

**SUMMARY & RECOMMENDATIONS**

# Summary and Recommendations

## A need to raise awareness and knowledge of ATTR-CM for earlier detection

**Speed up the diagnosis pathway.** Patients experience a long and convoluted path to diagnosis, and hope it can be shortened.

**Raise awareness of small clues** and small symptoms amongst the general public and GPs, as these initial signs were often ignored or dismissed. Asymptomatic patients with suspected ATTR-CM in family members suggest earlier (genetic) testing.

**GP to play stronger role.** Patient experience indicates the potential for earlier diagnosis if HCPs could better track, record, and pay attention to patterns of seemingly mild symptoms, medical records/notes, and also diagnoses (e.g. carpal tunnel) that mask/disguise the underlying cause.

## Specific and up-to-date information in layman's terms is sought after

**General information** on ATTR-CM for the newly diagnosed patient and their carer is appreciated.

**Specific information.** However, many feel there is scarcity of specific information to help more advanced patients (and carers) plan for the future – e.g. lifestyle adjustments, ways to enhance their health/wellbeing, and end of life planning.

**Information on access to the latest treatments and trials is of interest,** leading some to read medical/clinical publications, which do not always enhance knowledge or understanding. Seeking information that is relevant and in layman's terms, or hope their HCPs can provide these updates, proactively.

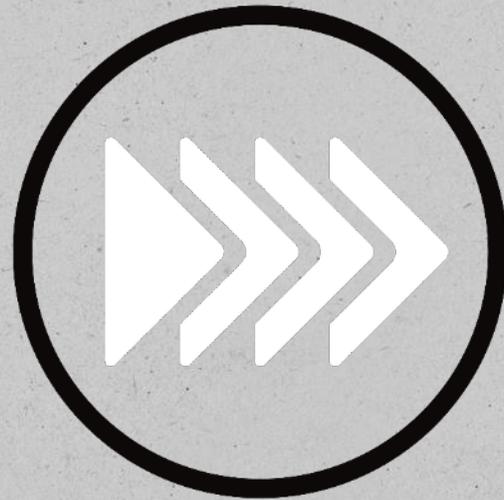
## Specific support and advocacy for ATTR-CM patients and carers

**Variability in prognosis** means patients and carers tend to live in fear and uncertainty.

**Psychological support** and groups that can address unique needs of ATTR-CM patients is needed.

**Willingness to help future patients.** Participants on this community felt that while access to treatment options were likely to be limited for them, they hoped to contribute to helping future patients.

**Beyond support,** patients and carers are hoping for a more unified group to meet their desire to raise awareness, education, representation, for access to up-to-date treatment/trial information, and for greater connection with other ATTR-CM patients/carers, locally and globally.



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