

DESIGNING FOR HOPE AND RESILIENCE:

Reimagining care for patients with chronic
pancreatitis and recurrent acute pancreatitis

Mission:Cure



**The team at Mission: Cure thanks
the patients, caregivers, and
providers who took the time to
share their experiences and ideas.
Together their stories illuminate
the leap needed to provide holistic
and compassionate care to
pancreatitis patients to improve
their well-being.**

Introduction

Over the past three years, pancreatitis patients have shared consistently dismal experiences in navigating multiple providers and medical centers in search of a diagnosis and/or plan to manage the condition, while also suffering with pain, hopelessness, and poor outcomes. We believe it is important and possible to integrate patient voice, emerging research, and evidence-based standards of care to give patients a more holistic experience that incorporates the physiological, mental, social and emotional well-being of the patient. This report is a first step in that direction.

Over the past few months, Mission: Cure has spoken with individuals and caregivers of those diagnosed with or experiencing symptoms related to chronic pancreatitis or recurrent acute pancreatitis. We have also spoken with medical providers—including clinical researchers, academics, practicing

gastroenterologists, and neuroscientists—to document their perspectives on improving care for pancreatitis patients. This report aims to synthesize the experiences of patients and caregivers, highlight gaps in the current approach to care, and weave together concrete ideas shared by patients, caregivers, and providers to improve patient outcomes and quality of life. This builds on the survey results presented in [“Listening to the Voices that Matter: Chronic and Recurrent Acute Pancreatitis Patient Perspectives,”](#) first published by Mission: Cure in 2018 and subsequently updated in 2019.

What is Chronic Pancreatitis?

Chronic pancreatitis is inflammation of the pancreas, the organ that produces digestive enzymes and insulin. The inflammation leads to scarring, which causes severe digestive problems and, eventually, diabetes. Chronic pancreatitis patients experience extreme pain and are at exceptionally high risk for pancreatic cancer. Chronic pancreatitis affects more than 200,000 Americans and over a million people worldwide. It is a heterogeneous disease that affects both children and adults. People with chronic and recurrent acute pancreatitis have very high hospital utilization rates. Acute pancreatitis is the most frequently documented discharge diagnosis (> 270,000 per year) for hospitalizations caused by gastrointestinal diseases.

About Mission: Cure

Mission: Cure was established in 2017 to improve patient outcomes and to find effective treatments, and ultimately a cure, for pancreatitis. Mission: Cure is pioneering innovative approaches along four key dimensions to achieve our goals:

- **patient engagement** to elevate our patient community and its collective needs, strengths and voice;
- **cure strategy** to accelerate the development of the most promising projects, ranging from pre-clinical research such as developing new pancreatitis models in the lab, to translational research, focused on drug repurposing, precision medicine and innovative trial designs;
- **technology advancements** in genomics and big data to collect, analyze and share key information to advance new therapies and cures; and
- **innovation in funding**, building on trends in impact investing and outcomes-based financing, to create new incentives based on measurably-improved patient outcomes.

Together, these four dimensions are moving us closer than ever to a world without pain and suffering from pancreatitis.

There are three goals for sharing this report:

1. Create a Shared Understanding of the Patient Experience:

Pancreatitis is a complex heterogeneous disease that impacts an individual's social, emotional, mental, and physiological well-being. However, the condition's toll on quality of life is not widely understood by the general public or the medical community. This report highlights the patient experience based on comprehensive conversations with 20 caregivers and patients.

2. Distill Patient Needs and Provider Perspectives to Reimagine Care:

In our conversations, patients and caregivers were encouraged to share ideas and approaches that they consider central to their care and experience with medical providers. Providers were asked to share their ideas on best practices and opportunities to improve patient outcomes. This report weaves together several ideas and approaches shared by interviewees and presents four concrete ideas to reimagine care.

3. Establish Partnerships and Collaborations to Improve Patient Care:

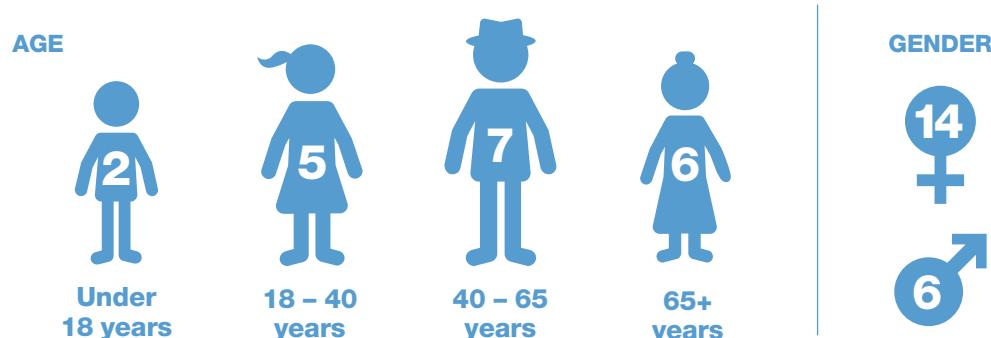
Since its inception, Mission: Cure has taken a collaborative approach to bring together patients, researchers, practitioners, and other stakeholders to pursue its mission. Building on that stance, we hope that this report will spark an actionable dialogue with providers, payers, and other stakeholders to drive measurable improvement in patient outcomes and experience.

Methodology for Conducting Patient Interviews

- Conducted outreach to invite patients and caregivers to share their experiences individually. To gain a deep understanding of the patient experience, which could not be acquired through online surveys or focus groups, we took the approach of experiential interviews. Using Mission: Cure's database and social media platforms, we invited patients and caregivers to sign up for individual interviews. Our goal was to speak to a diverse group of patients and caregivers, including pediatric and adult patients living in rural or urban settings. A total of 20 interviews* were completed on a rolling basis over a period of ten weeks.

Patient Profile

Mission: Cure staff created 20 patient profiles, using personal testimonies and second-hand descriptions shared by caregivers and providers.



* A MIT Sloan study suggests that in-depth one-on-one interviews with ten to twenty users per segment should be adequate to identify user needs.

TYPE OF PANCREATITIS	12 chronic	5 hereditary (pediatric)	3 recurrent acute
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Personas are fictional composite characters based on data from real people. They bring “real people” to the table rather than just quantitative data.

- **Led open-ended conversations through video or audio calls.** Building on tools and practices used by artists, anthropologists, and ethnographers, Mission: Cure developed a semi-structured approach to create an open and safe space for patients and caregivers to share their stories in their own words and at their own pace. Interviewees were asked to describe themselves, share their experiences living with pancreatitis, and offer ideas of ways to improve their care experience. Caregivers were invited to not only share the perspective of patients, but also their own experiences in supporting patients. During the conversation, we also asked follow-up questions. None of the questions were required for the completion of the interview, giving interviewees an opportunity to limit their response to what they felt comfortable sharing. All interviewees were granted anonymity. For each conversation, participants’ verbatim words and non-verbal cues, such as tone of voice, body language, and changes in emotions, were noted to the greatest possible extent, with the aim of fully capturing their experiences.
- **Synthesized notes and aggregated insights across multiple interviews.** After debriefing our interview notes, we created comprehensive subject profiles for a total of 20 patient experiences, including those of patients that we interviewed ourselves as well as patient experiences described by caregivers. The subject profiles were used to create patient and caregiver personas to highlight common underlying unmet needs, important differences in care experience, and other themes presented in multiple interviews. The qualitative information from the interviews was coded in a spreadsheet to organize patients by age, gender, geographical region, type of diagnosis, access to an academic medical center, etc.
- **Documented provider perspective to improve patient care and outcomes.** We spoke with 15 providers, including gastroenterologists, clinical researchers, academics, neuroscientists, nurse practitioners, and therapists. Our goal was to understand their current approach to caring for patients, opportunities to improve patient care and outcomes, and resources or time constraints that should be considered as we reimagine care.

Current Patient Experience: Living with Hopelessness and Poor Outcomes

Our goal was to understand how patients and caregivers navigate diagnosis and care, identify common underlying unmet needs, and understand factors that resulted in different outcomes and/or experiences. While the size of the data set limits our ability to generalize, below we share four themes that were consistently raised:

Limited understanding of pancreatitis results in delayed diagnosis or misdiagnosis of patients

Out of the 20 patients in our sample, twelve patients were diagnosed after multiple years—ranging from two to 50—of suffering.

Patients noted being misdiagnosed with conditions such as a sensitive stomach, gallbladder malfunctioning, irritable bowel syndrome (IBS), or appendicitis, or were told it was “in their head.” Several patients expressed frustration with providers failing to thoroughly investigate possible causes of their illness, and quickly brushing them off or sending them home when clinical tests or scans showed inconclusive results. In one case, a provider was reluctant to diagnose the patient with a “pancreatic issue” because he was “taught in medical school not to mess with the pancreas,” according to the patient.

Research now indicates that while long-term, very heavy alcohol use can increase the risk of pancreatitis, alcohol does not directly cause the disease.

Rather it’s a combination of genetic and environmental factors that typically result in pancreatitis. However, the stigmatization of patients still exists, especially for patients who just drink socially, which deters them from seeking help. Many patients described unpleasant encounters with doctors who were quick to undermine their symptoms or label them as alcoholic on medical records rather than answer their pleas for help.

“They say that pancreatitis is for overweight, alcoholic, old patients, and tell me I’m not a typical pancreatitis patient.”

“The biggest hurdle is the medical community...they always attribute it to alcohol and thought my 12-year-old son was drinking when he was diagnosed.”

One patient with a history of alcohol dependence and anxiety sought treatment for his flare-ups when he could not self-manage. He reported being humiliated by doctors and nurses during his first two visits to the emergency room (ER):

“The ER staff made me feel like ‘you did [this] to yourself, there is nothing we can do about this’, which discouraged me from going to the ER next time...”

“I was close to dying at one point but refused to go to the doctor because of the humiliating treatment.”

Overwhelmed by emotional trauma, he sought care at different hospitals for each subsequent flare-up which disrupted his care and caused a sepsis-related near-death experience. After four painful visits to the ER, a doctor finally found a large pancreatic cyst that was infected and performed surgery that same day.

Misdiagnosis and/or delayed diagnosis not only prevents access to proper care and support but also limits access to therapies that could delay the progression of the disease. For some patients, delayed diagnosis had caused irreversible damage to the pancreas from years of scarring and inflammation.

Outdated and inconsistent standards of care severely impact patients’ quality of life

“[When my doctor told me] ‘you have chronic pancreatitis. You will have a lifetime of pain, good luck’...I thought my life was over.”

Patients who did receive a diagnosis were often left on their own to understand and manage the condition. Several patients and caregivers reported feeling hopeless and extremely depressed when the diagnosis was followed by no explanation of the

disease and no conversation around a treatment and/or management plan. They relied on fragmented online resources and support groups to get answers to their questions with minimal medical support.

“Reading is so discouraging for me; the people who post online can’t leave their beds—I’m scared that it’s going to get so much worse.”

“Every specialist you go to wants to do something different, different tests—they don’t have a protocol they follow.”

Patients also noted multiple visits to different doctors and specialists in search of a plan to manage the disease. They cited frustration with specialists delivering conflicting advice and attempting different tests and scans during each visit. These visits to various doctors, surgical interventions that did not necessarily

“...for pain relief...[my insurance has] burned through at least half a million dollars in the past two years.”

relieve pain, and multiple trips to the emergency room left patients with large medical bills and hostile calls with insurance companies, but no plan to manage the condition.

Out of the 20 patients in our sample, 16 patients currently receive care at academic medical centers.

Patients who had the emotional, financial, and/or intellectual means to advocate for themselves and find support for their pain and symptoms attempted to do so. Some of them traveled to different parts of the country to seek care at various academic centers with expertise in pancreatic issues, hundreds of miles away from their homes. Most of the patients who did not receive care at an academic center did not have a plan or a reliable team of doctors to manage their condition; they shared their local providers' hesitation to consult with or provide referral to other physicians specializing in pancreas-related diseases even when it was clear that the local provider had a limited understanding of the condition.

Caregivers of pediatric patients shared similar experiences as they devoted their life to advocate for their child's needs. One mother spoke with the administrations of several hospitals to hold the medical staff accountable for disrespecting or refusing to treat her daughter. She also leveraged her experience as a social worker to lead training sessions for medical staff on how to care for pain patients with empathy.

“As an adult, I am taken less seriously than I was as a child.” —an adult patient who grew up with pediatric pancreatitis

While a pediatric patient may receive quality care at a children's hospital, it does not guarantee that s/he will receive similar care into adulthood. One patient, diagnosed with chronic pancreatitis at the age of nine, noted the difference in the quality of care as she transitioned from a pediatric hospital to an adult medical center. She is now labeled as a “drug seeker” rather than a pancreatitis patient when she goes to the emergency room for an acute flare up.

Minimal support with managing pain adds to patient anxiety and reduces quality of life

“The best way to describe the pain is [as] if someone took a burning hot knife and stabbed it into your gut...or maybe you had battery acid poured into your system... [the pain] is overwhelming and can’t be tolerated.”

Pancreatitis patients live with a fear of flare-ups—episodes of debilitating pain that can last one to three weeks—which leave them bedridden and incapacitated. However, patients are often afraid to ask for pain medication due to fears of being labeled as drug-seekers:

“[A doctor treated me like] a criminal on trial and not a patient seeking help.”

Several female patients reported being refused pain medication explicitly on the basis of their gender:

“I was told by a doctor that I was exaggerating the pain [because] I am a woman.”

Patients who were prescribed painkillers to manage pain were mostly given one or two options with no alternatives, even when the prescribed medicine was not a good fit for the pain or created other complications. Patients wished that their pain and suffering were acknowledged by their providers, rather than being disregarded and dismissed.

The disease’s impact on mental well-being is rarely discussed or addressed

“You can drown if you do not have support or doctors who listen to your emotions.”

The combination of the debilitating pain and lack of reliable information on pancreatitis can often be intimidating and isolating for patients who have just received the diagnosis and never heard of the condition.

In our sample set of 20, nine patients were diagnosed with mental health issues, such as depression, anxiety, panic attacks, and post-traumatic stress disorder, co-occurring with pancreatitis. Of those nine patients, two reported experiencing suicidal ideation and having to quit work or drop out of school. Another three patients who did not report mental health diagnoses currently see a therapist, counselor, or a psychiatrist.

“I couldn’t function anymore and would make mistakes that would cost the company millions of dollars.”

“I don’t have the energy for social plans; (I) used to go to concerts, trips, shopping, and do fun cool things but now I don’t.”

The excruciating pain combined with mental health issues often impaired patients’ abilities to fully engage in school, work, and other commitments. Of the 18 adult patients interviewed, five adult patients were retired and another five were unable to work because of pancreatitis related symptoms. Nearly all patients shared how limited diet, financial burdens of the disease, and/or anxiety related to the sudden onset of a flare up severely diminished their ability to sustain relationships and maintain a social life.

“My feelings with the disease are now dominating my life.”

In addition to affecting the patients, pancreatitis was also shown to impact the mental health of caregivers, including parents, partners, and other family members. Partners of adult patients took on multiple roles—as chaperones to drive them to medical appointments, as advocates at medical centers and with insurance companies, and as therapists to help them manage the daily toll of the disease. Parents of young patients reported extreme mental and physical exhaustion as they navigated the medical system, debated with insurance companies, and helped their child manage the condition.



Peter Fraser

Age: 67

Occupation: Retired after a successful career in biotechnology

Status: Married with three adult children

Enjoys: Board games and golfing

A retired man who confidently advocates for himself

Peter retired after a successful career in biotechnology and science. Given his professional background, he is comfortable with technical terms and spends a significant time doing research online about pancreatitis. He is financially secure and willing to travel all across the country to receive top-notch care. Peter is not afraid to ask questions and communicate his needs to his providers.

“You feel alone as a patient. I want to develop a plan. If you have a plan, you have hope.”

Peter’s Journey

Peter started experiencing severe abdominal pain in his 30s. He received a diagnosis of chronic pancreatitis soon thereafter but struggled to find an approach to manage the condition. He frequently visited the ER with acute episodes of pain and would be discharged with some temporary pain relief but no concrete plan. He spent all of his free time researching about pancreatitis and engaging with online support groups.

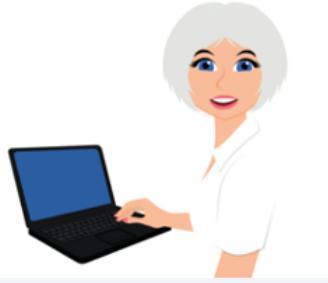
After four years and visiting 15 different gastroenterologist specialists with no clear answers, Peter was willing to try anything.

“I had a pretty quick diagnosis, but what to do about it was long in coming.”

“When doctors run into a wall, they don’t handle it very well.”

After a particularly severe pain episode that left him debilitated for a week, Peter traveled to three different centers in search of a plan to manage his condition. He finally settled on an academic pancreatic program closest to his home and was able to find doctors who listened. The gastroenterologist (GI) connected him to a dietitian and helped him put together a plan, including pancreatic enzymes and gabapentin to manage neuropathic pain.

Peter has not been to the ER in the last two years. Today, he can detect an oncoming flare-up and knows how to manage the pain. He sees his local GI twice a year and meets the specialist at the academic center once every two years.



Caroline Fraser

Age: 64

Occupation: Retired

Status: Peter's wife and caregiver, mother of three adult kids.

A partner and caregiver who fills in the gaps of expertise

"Caregiving has turned into a full-time job...it's a lot."

Caroline and Peter recently celebrated their 45th wedding anniversary. Caroline often reflects on the ups and downs that she has navigated with Peter by her side; her proudest moments were watching her three children grow into adults and having families of their own.

When her husband was diagnosed with chronic pancreatitis, Caroline's life seemed to fall apart. While she was completely shaken up, she stepped up to provide Peter her unconditional love and support, especially on days when the pain and nausea is unbearable. Caroline retired a few years ago from a mid-size company and hopes to enjoy her golden years with her family and grandkids.

Caroline's Journey

"They sometimes share his medical records between hospitals but only with heavy prompting from me."

Over time, Caroline has learned to assist Peter in many aspects of his care, enabling him to be a strong advocate for himself. She travelled with him across the country as he sought a plan to manage pancreatitis. She makes time to drive Peter to his appointments and joins the consultations to share her observations and get answers to her questions.

She often finds herself over phone fighting with insurance companies to authorize treatments that he needs or to correct erroneous charges. She manages Peter's strict diet plan and frequently asks his dietitian questions about the food triggers for flare-ups.

"Sleep deprivation has been a big issue for me."

Sometimes Caroline is overwhelmed with all the different aspects of care and wishes that she could access mental health support as a caregiver.



Sarah Walker

Age: 38

Occupation: Software engineer

Status: Married with two young daughters

Enjoys: Lounging at the beach with her family

A hard-working engineer and mother who is worried for what is in store for her daughters

Sarah met her husband in high school and married him soon after she graduated from college. Her husband's job requires him to be on the road for extended time so she is the main caregiver for their two daughters. While she has been suffering for the last decade, she was recently diagnosed with chronic pancreatitis. Until a few months ago, she worked as a software engineer at a consumer service company. However, she recently lost her job because she was on leave for too many days. The stress is taking a toll on her mental health but she has no time to seek therapy because she has to care for her children.

"I am tired of carrying my medical records just to prove that I am not an alcoholic who is a drug addict, especially with kids in tow..."

Sarah's Journey

Sarah first experienced intense abdominal pain, back pain, nausea, and vomiting about 10 years ago. Her PCP diagnosed her with GERD and prescribed Zantac, which did not alleviate her symptoms. She continued to experience pain and over the next five years was in and out of the hospital, dragging her little girls along with her. One year, she had to miss multiple family celebrations because of her recurrent trips to the hospital.

"Every specialist you go to wants to do something else different. They don't have a protocol they follow."

"My doctor told me that I was exaggerating the pain because I am a woman."

Sarah saw at least seven specialists in her suburban town but they all proposed different treatments. Many also told her to quit abusing alcohol even though she had only ever had one or two glasses of wine in social settings.

“If you are having more trouble, come back to the ER.”

During her visits to the hospital, ER physicians

would perform scans, find nothing abnormal, and send her back home without prescribing the pain medication that she needed.

She was often labeled as a drug seeker and told that she was not presenting with the “right symptoms.” In pain and with no support, Sarah felt like giving up on some days. She imagined herself in a dark train car hurtling down bumpy tracks waiting for an inevitable fatal crash.

With no pathway in sight, she changed her insurance plan from an HMO plan to a PPO because her doctor refused to refer her to a pancreas specialist she had found through her online research. The specialist listened to her intently, asked questions, and conducted an endoscopic ultrasound. Sarah was finally diagnosed with chronic pancreatitis.

“I hope they come up with a medicine that helps treats us...I hope I don't get worse...I know this condition is only going to get worse...”

Since then, the specialist has been a champion for her. He reached out to her primary care physician to share the diagnosis. His care coordinator checks in periodically with Sarah and provides referrals to tests.

Given the delay in her diagnosis, her pancreas is quite scarred and the specialist has suggested total pancreatectomy with islet auto transplantation (TPIAT) as an option to manage her pain. While her diagnosis gives her some relief, she is worried for her daughters because the results of her genetic testing show multiple risk factors.

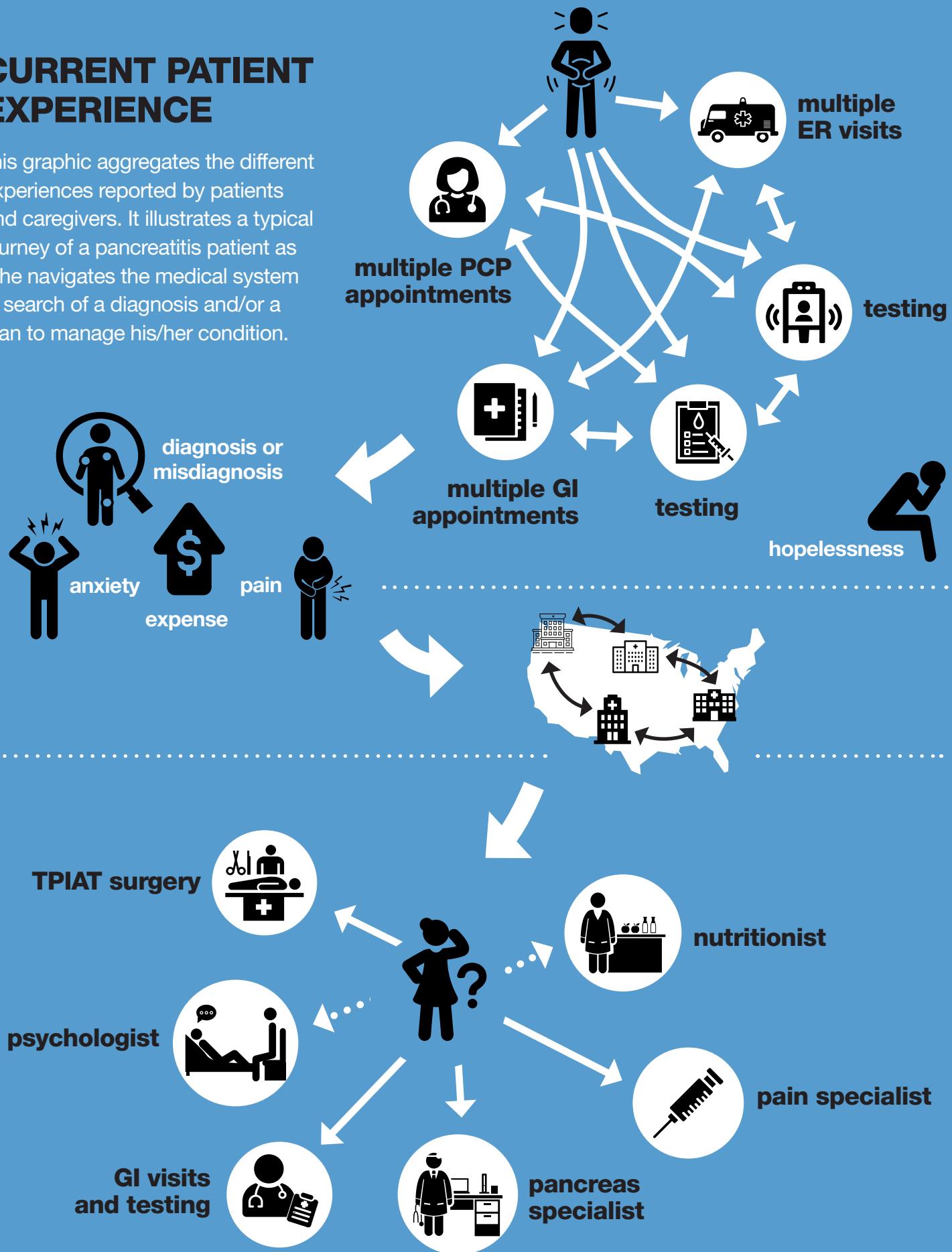
The family is now relocating to another state because of her husband's job.

“I am worried for my daughters...I don't want them to experience this.”

Sarah is optimistic and has already started searching for a specialist close to her new hometown. She has also joined a few online support groups and finds solace and advice from other patients going through similar experiences.

CURRENT PATIENT EXPERIENCE

This graphic aggregates the different experiences reported by patients and caregivers. It illustrates a typical journey of a pancreatitis patient as s/he navigates the medical system in search of a diagnosis and/or a plan to manage his/her condition.



Reimagining Care: Creating Hope and Resilience

In our conversations, patients, caregivers and providers shared ideas to improve the experience of pancreatitis patients. Below, we highlight four strategies to improve the patient experience and outcomes that are concrete and mutually reinforcing. A combination of these strategies is already in place in certain medical centers, and we hope to spread and scale these practices so that all patients can access high-quality care.

Comprehensive Standards of Care that Prioritize Patient Outcomes

[As a GI practitioner, I have observed that] the mindset is more like what procedure can I do for you but not much focus on how to manage this.”

“I want my patients to feel empowered to take control of the dialogue...”

Patients and caregivers expressed a need for a standard protocol that can be used by medical providers when serving patients with symptoms related to chronic or recurrent acute pancreatitis. Several aspects of care were noted:

- **a consistent set** of tests and diagnostics to avoid misdiagnosis and/or delayed diagnosis;
- **a tiered management plan** that considers the unique symptoms presented by each patient and lays down a set of options to manage diet, pain, mental well-being, and surgical or endoscopic interventions, as needed;
- **tracking of patient outcomes** to adjust and adapt the plan and proactively delay the progression of the disease; and
- **a plan to recover** from flare-ups, including self-management at home and ability to access testing and intravenous fluids at a local medical center, before heading to a hospital’s emergency room.

A comprehensive care protocol that prioritizes patient outcomes will empower both patients and their providers to be in control of managing pancreatitis.

Multi-disciplinary and Coordinated Care to Manage Pancreatitis and Related Conditions

“I wish [physicians] were honest about what they did or did not know and willing to receive counsel from experts.”

“[I want] doctors that take me on and say we are going to solve this together, and we will find a solution.”

Several patients, caregivers, and providers suggested a multi-disciplinary team of medical providers who understand the causes and presentation of pancreatitis and provide holistic care, including:

- **Pancreas care:** A team of local and remote gastroenterologists who specialize in pancreatic diseases to provide surgical, endoscopic, and other interventions.
- **Pain management:** Early access to pain management specialist(s) who work in close coordination with the patient to develop an integrated approach, including pharmacological and alternative therapies, to provide a personalized pain management plan.
- **Mental wellbeing:** Mental health experts to help patients manage the fear and anxiety of an impending flare-up, recognize and regulate emotions that may trigger a flare-up, learn skills to communicate with providers and advocate for their needs, “listen” and adhere to their treatment plan, and adapt their lifestyle to best manage pancreatitis.
- **Wholesome diet:** A dietitian who can help manage the nutritional deficiencies that can result from pancreatitis such as malabsorption and pancreatic exocrine insufficiency, help identify food triggers, and work to create a personalized diet plan for patients, including suggestions on how to participate in social settings.
- **Care coordination:** A central advocate to help patients navigate through medical and non-medical issues, such as applying for disability and coordinating referrals and flow of information between different providers. Caregivers of young patients highlighted the need for a structured handoff from pediatric to adult providers to enable a smooth transition.

Patients and providers both brought up the advantages of telemedicine as they shelter-in-place during the COVID-19 pandemic.

“I have been doing video consults these last few months. I can see how they [patients] live. [It] helps me to provide actionable advice in their local context”

“I have had zoom appointments with my doctor. They are great, I don’t have to drive three hours to see him.”

“[I] really appreciate virtual appointments because sometimes I am in too much pain to get out of bed.”

Provider Education that Integrates Patient Experience and New Research

“It doesn’t seem like there is a lot of knowledge or information [in the medical community] about managing the condition.”

“Endoscopic procedures sometimes hurts people, and while some doctors are comfortable using the surgical knife to remove parts of the body, it’s not clear that it is helpful to treat the disease.” — an experienced gastroenterologist

Providers, patients and caregivers expressed a need to expand all aspects of medical training—residency, fellowships, and continuing medical education (CME)—to include insights from emerging research, evidence-based best practices, and patient experience to:

- create a deeper understanding of the causes and presentation of pancreatitis to overcome misinformation and bias about alcohol;
- assess, diagnose, and proactively manage pancreatitis;
- care for patients with respect, empathy, and a commitment for their health.

A Pathway to Information, Connection, and Hope

“I know there is research happening on my specific genetic mutation that may impact my condition. This gives me hope.”

To navigate the complex, technical, and sometimes incorrect information available online, patients and providers articulated a strong desire for a centralized clearinghouse for information about pancreatitis that is easy to understand. Patients suggested including information on causes of pancreatitis, therapies available to manage the condition, and promising approaches—such as clinical and drug repurposing trials—that are underway or soon to be launched that patients can track or participate in. These resources not only provide valuable information but are also a source of hope for patients and their caregivers as they live with pancreatitis.

Next Steps: Translating Ideas into Actions

These experiential conversations have been incredibly insightful and offer a roadmap as Mission: Cure strives to improve quality of care for patients that incorporates physiological, mental, social and emotional well-being. Below we share some next steps that we will further develop over the next few months.

- **Build Pathways to Information and Hope.** Over the past three years, we have convened experts, hosted webinars, and used our website and social media platforms to share information on pancreatitis. Encouraged by positive response from the patient community, we will continue to expand and deepen our efforts to share emerging research, best practices, and clinical trials underway or planned to keep patients and caregivers informed of new developments.
- **Engage Patients and Caregivers to Develop Equitable Access to Patient-Centered Care and Practices.** We have established a Patient and Caregiver Advisory Board (PCAB), a group of highly engaged patients and caregivers who will provide input and advice as we prioritize the development and spread of patient-centered practices and care model(s) for pancreatitis. The waivers granted to accommodate shelter-in-place orders for COVID-19 has expanded the use and acceptance of telemedicine. We want to leverage this window of opportunity to enable equitable and convenient access to care for pancreatitis patients.
- **Explore Partnerships with Medical Education Leaders and Experts.** We will work with new and existing partners to develop a strategy to integrate patient perspectives and priorities, emerging research, and evidence-based standards of care in the training received by medical providers, starting in medical school and on to continued medical education.

Furthermore, we acknowledge that more work must be done to understand the effects of factors such as race, ethnicity, and socioeconomic status on the prevalence, patient experience, and progression of the disease. We remain dedicated to building a fuller understanding of the diversity of patient perspectives and are continually taking steps toward hearing all voices of those affected by pancreatitis. We hope that by listening to the voices of those battling the disease, as well as those aiding in that battle, we can better understand and amplify their experiences, ultimately driving necessary dialogue and measurable improvement in patient experiences and outcomes.