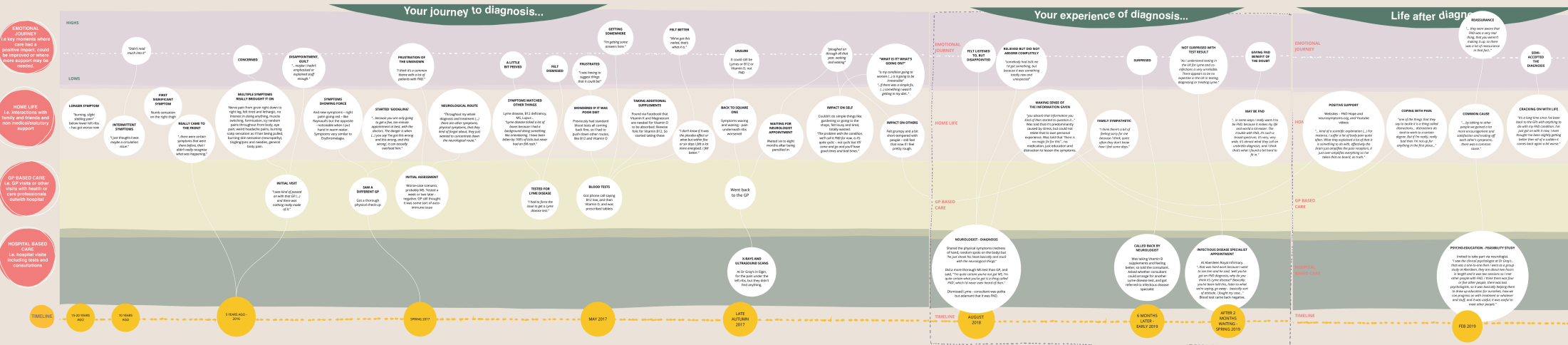


experience map  
*functional neurological disorder*



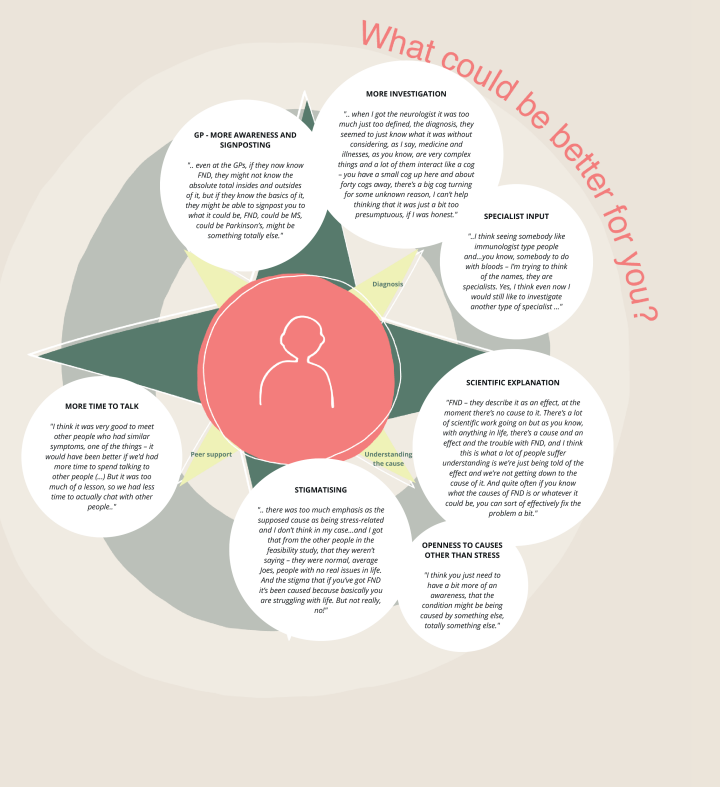
## What matters to you?

### See in detail on page 3



## Your journey

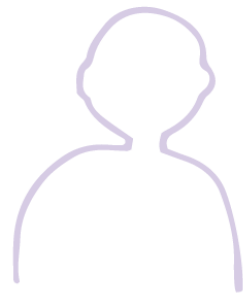
### See each panel in detail on pages 4-6



## What could be better for you?

### See in detail on page 7

# What matters to you?



About you...

## WAS FIT AND HEALTHY

*"Since I've had the condition, which has really been at its worse for the past five years, that's considerably lessened."*

## TOPSY-TURVY

*"I was potentially looking for a part-time job just to keep me ticking over but with the condition being topsy-turvy and mucking me about, I've kind of put that on hold."*

## NOT DRIVEN BY STRESS

*"I just want to emphasise the point that there's a lot being said that FND is being driven by stress and I honestly think, in my personal case, that has probably not been the issue."*

## CONTROLLED STRESS

*"It was stressful, but it was controlled stress and it was good stress, if you know what I mean."*

## RETIRED

At age 55 from the Royal Air Force. Flew on Nimrods, did ground chores and in the last job at Rescue Coordination Centre was dealing with the rescue helicopters

## SPORTY

Have done mountain biking and sport, orienteering, cross-country running, road running, races, marathons and stuff like that

How you spend your time

How your condition(s) affects you

## INTERESTS

Hill walking (been limited with the Covid restrictions), research into aircraft wrecks – World War II aircraft crashes and wreck sites

## Family

Live in Forres.

## HAPPILY MARRIED

Wife - has a part-time job working at the local primary school, and two children - daughter in second year of university and son in S5.

*"Generally life is quite good for us."*

## LIFE IS NORMAL

No financial issues, retired, no compounding factors.

59 years old.

## Career

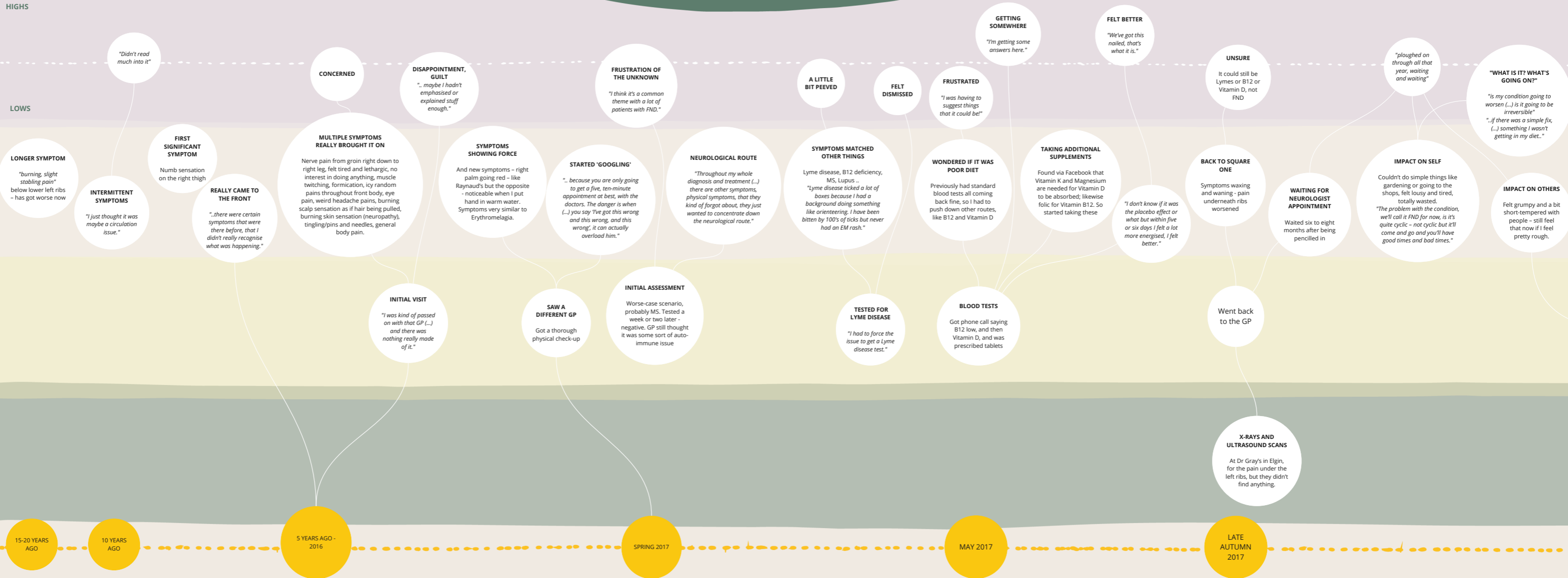
# Your journey to diagnosis...

**EMOTIONAL JOURNEY**  
i.e. key moments where care had a positive impact, could be improved or where more support may be needed.

**HOME LIFE**  
i.e. interactions with family and friends and non medical/statutory support

**GP BASED CARE**  
i.e. GP visits or other visits with health or care professionals outwith hospital

**HOSPITAL BASED CARE**  
i.e. hospital visits including tests and consultations



**TIMELINE**

15-20 YEARS AGO

10 YEARS AGO

5 YEARS AGO - 2016

SPRING 2017

MAY 2017

LATE AUTUMN 2017

HIGHS

LOWS

**LONGER SYMPTOM**

"burning, slight stabling pain" below lower left ribs - has got worse now

**INTERMITTENT SYMPTOMS**

"I just thought it was maybe a circulation issue."

**FIRST SIGNIFICANT SYMPTOM**

Numb sensation on the right thigh

**REALLY CAME TO THE FRONT**

"...there were certain symptoms that were there before, that I didn't really recognise what was happening."

**MULTIPLE SYMPTOMS REALLY BROUGHT IT ON**

Nerve pain from groin right down to right leg, felt tired and lethargic, no interest in doing anything, muscle twitching, formication, icy random pains throughout front body, eye pain, weird headache pains, burning scalp sensation as if hair being pulled, burning skin sensation (neuropathy), tingling/pins and needles, general body pain.

**SYMPTOMS SHOWING FORCE**

And new symptoms - right palm going red - like Raynaud's but the opposite - noticeable when I put hand in warm water. Symptoms very similar to Erythromelalgia.

**STARTED 'GOOGLING'**

"... because you are only going to get a five, ten-minute appointment at best, with the doctors. The danger is when (...) you say 'I've got this wrong and this wrong, and this wrong', it can actually overload him."

**NEUROLOGICAL ROUTE**

"Throughout my whole diagnosis and treatment (...) there are other symptoms, physical symptoms, that they kind of forgot about, they just wanted to concentrate down the neurological route."

**SYMPTOMS MATCHED OTHER THINGS**

Lyme disease, B12 deficiency, MS, Lupus ...  
"Lyme disease ticked a lot of boxes because I had a background doing something like orienteering. I have been bitten by 100's of ticks but never had an EM rash."

**WONDERED IF IT WAS POOR DIET**

Previously had standard blood tests all coming back fine, so I had to push down other routes, like B12 and Vitamin D

**TAKING ADDITIONAL SUPPLEMENTS**

Found via Facebook that Vitamin K and Magnesium are needed for Vitamin D to be absorbed; likewise folic for Vitamin B12. So started taking these

"I don't know if it was the placebo effect or what but within five or six days I felt a lot more energised, I felt better."

**BACK TO SQUARE ONE**

Symptoms waxing and waning - pain underneath ribs worsened

**WAITING FOR NEUROLOGIST APPOINTMENT**

Waited six to eight months after being pencilled in

**IMPACT ON SELF**

Couldn't do simple things like gardening or going to the shops, felt lousy and tired, totally wasted.  
"The problem with the condition, we'll call it FND for now, is it's quite cyclic - not cyclic but it'll come and go and you'll have good times and bad times."

**IMPACT ON OTHERS**

Felt grumpy and a bit short-tempered with people - still feel that now if I feel pretty rough.

"Didn't read much into it"

**CONCERNED**

**DISAPPOINTMENT, GUILT**

"... maybe I hadn't emphasised or explained stuff enough."

**FRUSTRATION OF THE UNKNOWN**

"I think it's a common theme with a lot of patients with FND."

**A LITTLE BIT PEEVED**

**FELT DISMISSED**

"I was having to suggest things that it could be!"

**FRUSTRATED**

"I was having to suggest things that it could be!"

**GETTING SOMEWHERE**

"I'm getting some answers here."

**FELT BETTER**

"We've got this nailed, that's what it is."

**UNSURE**

It could still be Lyme or B12 or Vitamin D, not FND

"ploughed on through all that year, waiting and waiting"

**"WHAT IS IT? WHAT'S GOING ON?"**

"is my condition going to worsen (...) is it going to be irreversible"  
"...if there was a simple fix, (...) something I wasn't getting in my diet."

Went back to the GP

**X-RAYS AND ULTRASOUND SCANS**

At Dr Gray's in Elgin, for the pain under the left ribs, but they didn't find anything.

# Your experience of diagnosis...

## EMOTIONAL JOURNEY

**FELT LISTENED TO, BUT DISAPPOINTED**

**RELIEVED BUT DID NOT ABSORB COMPLETELY**

*"somebody had told me I'd got something, but because it was something totally new and unexpected"*

**SURPRISED**

**NOT SURPRISED WITH TEST RESULT**

*"As I understand testing in the UK for Lyme and co-infections is very unreliable. There appears to be no expertise in the UK in testing, diagnosing or treating Lyme."*

**GIVING FND BENEFIT OF THE DOUBT**

## HOME LIFE

**MAKING SENSE OF THE INFORMATION GIVEN**

*"you absorb that information you kind of then started to question it..."*  
Was told that it's predominantly caused by stress, but could not relate that to own personal experience. Was told that *"there is no magic fix for this"*.. no medication, just education and distraction to lessen the symptoms.

**FAMILY SYMPATHETIC**

*"I think there's a bit of feeling sorry for me because I think, quite often they don't know how I feel some days."*

**MAY BE FND**

*".. in some ways I really want it to be FND, because it makes my life and world a lot easier. The trouble with FND, it's such a broad spectrum, it's very, very wide, it's almost what they call an umbrella diagnosis, and I think that's what I found a bit hard to fit in."*

## GP BASED CARE

**NEUROLOGIST - DIAGNOSIS**

Shared the physical symptoms (redness of hand, random spots on the body) but *"he just shook his head basically and stuck with the neurological things"*

Did a more thorough MS test than GP, and said, *"I'm quite certain you've not got MS, I'm quite certain what you've got is a thing called FND; which I'd never even heard of then."*

Dismissed Lyme - consultant was polite but adamant that it was FND.

**CALLED BACK BY NEUROLOGIST**

Was taking Vitamin B supplements and feeling better, so told the consultant. Asked whether consultant could arrange for another Lyme disease test, and got referred to infectious disease specialist

**INFECTIOUS DISEASE SPECIALIST APPOINTMENT**

At Aberdeen Royal Infirmary. *"..that was hard work because I went to see him and he said, 'well you've got an FND diagnosis, why do you think it's Lyme disease?' Basically: you've been told this, listen to what we're saying, go away - basically sort of attitude. I fought my case..."*  
Blood test came back negative.

## TIMELINE

AUGUST 2018

6 MONTHS LATER - EARLY 2019

AFTER 2 MONTHS WAITING - SPRING 2019

# Life after diagnosis

## EMOTIONAL JOURNEY

### REASSURANCE

"... they were aware that FND was a very real thing, that you weren't making it up, so there was a lot of reassurance in that fact.."

### SEMI-ACCEPTED THE DIAGNOSIS

## HOME

### POSITIVE SUPPORT

Websites – FND Hope and neurosymptoms.org, and Youtube videos

"... kind of a scientific explanation (...) For instance, I suffer a lot of body pain quite often. What they explained a lot of that is is something to do with, effectively the brain just amplifies the pain receptors, it just over-amplifies everything so I've taken that on board, as truth."

### COPING WITH PAIN

"one of the things that they say to tackle it is a thing called distractions... distractions do tend to work to a certain degree. But if I'm really, really bad then I'm not up for anything in the first place..."

### COMMON CAUSE

"... by talking to other people we gained a lot more encouragement and satisfaction and trading off each other's symptoms, there was a common cause."

### CRACKING ON WITH LIFE

"It's a long time since I've been back to the GPs with anything to do with my FND condition. I've just got on with it now, I even thought I've been slightly getting better then all of a sudden it comes back again a bit worse."

## GP BASED CARE

### PSYCHO-EDUCATION - FEASIBILITY STUDY

Invited to take part via neurologist.  
"I saw the clinical psychologist at Dr Gray's, that was a one-to-one then I went as a group study at Aberdeen, they are about two hours in length and it was two sessions so I met other people with FND, I think there was four or five other people, there was two psychologists, so it was basically helping them to draw up education for ourselves, how we can progress on with treatment or whatever and stuff, and it was useful, it was useful to meet other people."

## HOSPITAL BASED CARE

## TIMELINE

FEB 2019

# What could be better for you?

## GP - MORE AWARENESS AND SIGNPOSTING

".. even at the GPs, if they now know FND, they might not know the absolute total insides and outsides of it, but if they know the basics of it, they might be able to signpost you to what it could be, FND, could be MS, could be Parkinson's, might be something totally else."

## MORE INVESTIGATION

".. when I got the neurologist it was too much just too defined, the diagnosis, they seemed to just know what it was without considering, as I say, medicine and illnesses, as you know, are very complex things and a lot of them interact like a cog - you have a small cog up here and about forty cogs away, there's a big cog turning for some unknown reason, I can't help thinking that it was just a bit too presumptuous, if I was honest."

## SPECIALIST INPUT

"..I think seeing somebody like immunologist type people and...you know, somebody to do with bloods - I'm trying to think of the names, they are specialists. Yes, I think even now I would still like to investigate another type of specialist ..."

## SCIENTIFIC EXPLANATION

"FND - they describe it as an effect, at the moment there's no cause to it. There's a lot of scientific work going on but as you know, with anything in life, there's a cause and an effect and the trouble with FND, and I think this is what a lot of people suffer understanding is we're just being told of the effect and we're not getting down to the cause of it. And quite often if you know what the causes of FND is or whatever it could be, you can sort of effectively fix the problem a bit."

## OPENNESS TO CAUSES OTHER THAN STRESS

"I think you just need to have a bit more of an awareness, that the condition might be being caused by something else, totally something else."

## STIGMATISING

".. there was too much emphasis as the supposed cause as being stress-related and I don't think in my case...and I got that from the other people in the feasibility study, that they weren't saying - they were normal, average Joes, people with no real issues in life. And the stigma that if you've got FND it's been caused because basically you are struggling with life. But not really, no!"

## MORE TIME TO TALK

"I think it was very good to meet other people who had similar symptoms, one of the things - it would have been better if we'd had more time to spend talking to other people (...) But it was too much of a lesson, so we had less time to actually chat with other people.."

Peer support

Understanding the cause

Diagnosis

