Helpful hints for living well with a GSD

Mental Wellbeing & Pompe Disease

pompe
AUSTRALIAN POMPE ASSOCIATION

This brochure has kindly been supplied by the Association for Glycogen Storage Disease (UK) Ltd
The information is intended to provide general information in regard to the matter covered. It is being reprinted and provided as a public service by the Australian Pompe Association to our members. Any information provided in this brochure that you seek to rely on should be discussed with you treating specialist or doctor. Any further information required should again be sought from your treating specialist or doctor.

Perspectives from people affected by Pompe disease

&

Build your own tool kit

Association for Glycogen Storage Disease UK
www.agsd.org.uk
April 2021

At the AGSD-UK conference in October 2019, Salford Nurse Tracey McGrae gave a round table session on mental health and Pompe disease. This had a huge impact on participants and we decided to gather some good ideas to share.

Contributors

Ben Parker	Pompe Support Team
Tracey McGrae	Clinical Nurse Specialist Salford Royal Mark Holland Metabolic Unit
Jane Lewthwaite	Specialist Care Advisor Pompe disease AGSD UK
Vicki Lucass	Editor

And….THE COMMUNITY !

We gathered quotes and suggestions, tips and contributions from our Pompe patient group. As always, we share and are keen to learn from one another. Often, this is the best advice anyone can get, from another person who is treading a similar path.

Thank you to everyone who contributed.

Important! This booklet cannot replace good, professional support. Use this as a handy guide. We simply share perspectives, information and stories that might point you in the right direction when you need help.

AGSD UK
Association for Glycogen Storage Disease

Mental Wellbeing & Pompe Disease

Messages from Pompe Support Team

The Pompe Support Team is here to provide support, information and raise awareness.

"At times trying to come to terms with the thoughts of living with Pompe disease can be really overwhelming and hard to deal with. By helping with this booklet I want to share ideas that worked for me in the hope that someone else can relate to them".

"Mental health is a lot for some to deal with who have able-bodies, but for those of us who have received a Pompe diagnosis this adds a whole new tier of worries, concerns and life changing adjustments. Don't suffer in silence and seek out the help you need".

"I am no doctor and I write from the heart. We are all human, we all feel joy, pain, happiness, sadness, shock, fear, love and the list goes on. When a diagnosis of a progressive condition such as Pompe is handed over to us, none of us know how to deal with it, there is no guide book and there is just this fact and your emotional reaction to it. Sometimes your reactions and thoughts can play havoc with your mental health".

John

Ben

Gemma

Angela

Donna

Contents

What are we talking about?
By Tracey McGrae, Clinical Nurse Specialist
- A brief description of mental health issues 4
- Panic Attacks: When anxiety gets out of hand 6
- A brief description of therapies 8
- Routes to mental health services 11
- The Stepped Care Model 12
- A list of services and names explained 14

Building your own tool kit explained 16
by Ben Parker and the UK Community
- Acceptance 18
- Practical ideas 20
- Therapeutic ideas 24
- Families, parents, carers and friends 26

Diagnosis with a Chronic Illness 28

Living with loss and Pompe disease 30

Acceptance and Commitment Therapy 32

Boom or Bust? The Importance of Spoon Theory 33

My Story: Anabel Rajgor 34
by Anabel Rajgor 2017

Shared tips from the mental health round-table AGSD-UK Conference 2019 38
By Tracey McGrae, Clinical Nurse Specialist

Sources of support and further information 40

A Message from Ben 44

Mental Health:
What are we talking about?

A brief description of mental health issues

By Tracey McGrae, Clinical Nurse Specialist

This booklet aims to help our community cope with daily life with Pompe disease.

What is depression?

Depression is not the same as being sad or experiencing grief, although it can be triggered by specific events. Many people will talk about not knowing why they feel the way they do, or not having any idea how to feel better. They will have been feeling like this for a long time, to the extent that it is interfering with their everyday life and stopping them doing things they would do normally.

A doctor will diagnose someone with depression by asking questions about whether they have certain thoughts and feelings, and how often.

How does depression affect people?

Someone who is experiencing depression will often describe feeling down, hopeless or empty. They can feel like they don't have any motivation and that it is impossible to enjoy anything anymore.

Everyone responds to depression in different ways. Some common behaviour that people with depression and their friends and family describe are:

- Cancelling plans with friends, or giving up hobbies they normally enjoy
- Staying in bed for long periods of time
- Changes in appetite
- Using drink or drugs more often
- Snapping at family and friends
- Avoiding or calling in sick to work, school or university

Anxiety is a normal emotion. When is anxiety a mental health problem?

Anxiety becomes a mental health problem when someone finds they are feeling anxious all or most of the time, to the extent that they are not able to do the things they would like to, or would normally do.

A doctor will diagnose someone with an anxiety disorder by asking them questions about how they think, feel and any physical symptoms they have.

A panic attack is when feelings of anxiety become intense and overwhelming. The person will normally experience physical symptoms including shortness of breath, sweating, an increased heartbeat or blurry vision.

How do anxiety and panic attacks affect people's lives?

There are many different types of anxiety problems and disorders. Everyone will experience it in different ways, for different periods of time and about different things.

People who experience problems with anxiety often describe life in general becoming exhausting, as the worry and fear associated with different situations takes so much energy to overcome. They can find it difficult to relax, sleep and eat. They might also avoid certain things, such as social situations, work or new and unfamiliar experiences.

A lot of people with anxiety problems will experience physical symptoms too, for example:

- Aches and pains
- Difficulty breathing
- Increased heart rate
- Hair loss
- Sweating
- Feeling sick or dizzy
- Blurry vision

Panic Attacks: When anxiety gets out of hand

From NHS website: www.nhs.uk/conditions/stress-anxiety-depression/understanding-panic

Symptoms of a panic attack

If you experience sudden, intense anxiety and fear, it might be the symptoms of a panic attack. Other symptoms may include:

- A racing heartbeat
- Feeling faint, dizzy or light-headed
- Feeling that you're losing control
- Sweating, trembling or shaking
- Shortness of breath or breathing very quickly
- A tingling in your fingers or lips
- Feeling sick (nausea)

"When my mind is a blur I struggle to concentrate. These are warning signs for me that I need to act and help myself and my mind".

A panic attack usually lasts 5 to 30 minutes. They can be very frightening, but they're not dangerous and should not harm you.

Things you can try to help with anxiety, fear and panic

Try talking about your feelings to a friend, family member, health professional or counsellor. You could also contact Samaritans, call: 116 123 or email: jo@samaritans.org if you need someone to talk to

- Use calming breathing exercises
- Exercise (running, walking, swimming and yoga can help you relax)
- Find out how to get to sleep if you're struggling to sleep
- Eat a healthy diet with regular meals to keep your energy levels stable
- Consider peer support, where people use their experiences to help each other. Find out more about peer support on the Mind website
- Listen to free mental wellbeing audio guides
- Search and download relaxation and mindfulness apps or online community apps from the NHS apps library

Things you shouldn't do

- Don't try to do everything at once – set small targets that you can easily achieve
- Don't focus on the things you cannot change – focus your time and energy into helping yourself feel better
- Don't avoid situations that make you anxious – try slowly building up time spent in worrying situations to gradually reduce anxiety
- Try not to tell yourself that you're alone; most people experience anxiety or fear at some point in their life
- Try not to use alcohol, cigarettes, gambling or drugs to relieve anxiety as these can all contribute to poor mental health

"I feel it is very hard to raise the topic of feeling low with medical teams, especially when it is a large group together. It would be really good if I was asked specifically about it more often, and that might help me to open up".

A brief description of therapies

Cognitive Behavioural Therapy

Cognitive Behavioural Therapy (CBT) is a type of therapy that works on making links between our thoughts, behaviour and actions. The idea is to focus on a specific area such as anxiety. If someone is anxious they may experience overwhelming thoughts sometimes over a specific issue e.g. a fear of falling in wet weather, this may impact on their actions so they may avoid going out in wet weather. As people avoid some actions or experiences this can create a higher anxiety about facing them in the future.

CBT practitioners aim to help analyse and challenge these thoughts with the person who has the anxiety to help adapt their thinking that they may not be able to change their environment, or stop things happening. However, they can change their thinking to reduce their anxiety.

"For me the benefit of counselling was sharing my worries and fears outside my family in a neutral place. However, the first counsellor did not click and I switched, the second was great".

Dialectical Behavioural Therapy

Dialectical Behavioural Therapy (DBT) is a type of CBT originally developed for people with borderline personality disorder. DBT works on dialectics which is a concept that everything is an opposite and that things will change with two opposing forces when one is greater than the other. It incorporates validation and self-belief helping the person undergoing the therapy to change their thinking about themselves as well as the anxiety they are feeling. Self-acceptance is key to DBT.

The core belief in DBT is that the person is worthy of change and that they deserve to change and tolerate distress. By learning skills, they can regulate their emotions and reduce their anxiety.

Mindfulness

Mindfulness has origins in meditation and Buddhist beliefs. However, it has evolved into a therapy to aid reduction of anxiety. Mindfulness works on acceptance of our thoughts without judgement. It prompts a heightened awareness of our environment and actions by having conscious thoughts around our body, its surroundings and out thoughts and feelings in the moment.

The suggested benefits of mindfulness is that if you are fully present in the moment without judgement or anxiety using meditation to relax and calm yourself you can reduce stress and anxiety.

"I tried counselling from my GP but they put me in to a group for self-esteem, it did not work so I located a private counsellor and although it was expensive it really worked well".

Person Centered counselling

Person or client-centered therapy is based on the view that everyone has the capacity and desire for personal growth and change, given the right conditions. Rather than being seen as the expert and directing the therapy, the counsellor offers unconditional positive regard, empathy and congruence to help you come to terms with any negative feelings and to change and develop in your own way.

Integrative counselling

Integrative counselling looks at the whole person, taking into account your mental, physical and emotional needs. Your therapist will use techniques and tools from different modalities to tailor an individual approach for you.

An integrative counsellor aims to build a trusting and non-judgmental relationship that helps you develop self-awareness. When you understand the causes of your concerns or triggers for your behaviour, you can confidently set goals and develop new behaviours to improve your satisfaction with life.

"Struggling with small tasks can feel demeaning;

I had to seek help to change my mindset and improve confidence".

Meditation

Meditation therapy is "a method of relaxation and consciousness expansion by focusing on a mantra or a keyword, sound, or image while eliminating outside stimuli from one's awareness" (Mosby's Medical Dictionary, 2009).

"Regular meditation lowers my anxiety and helps my mind to be clear and focused".

There are many types of meditation. Examples include mindfulness, body scan, loving-kindness, walking, Zen, mantra, and transcendental meditations. They can be further categorized into insight or calming and guided or unguided. In the world of meditation, there is an approach for everyone.

Social prescribing

Social prescribing looks at linking people with a practitioner who can look at other holistic ways to manage their mental health. This may include an assessment and an individualised care plan, investigating what the person wishes to focus on and what local services may be available to give them these possibilities.

Social prescribing looks primarily at people with long term conditions and brings in several interventions including benefits, community run projects, educational or vocational aspects and non-clinical interventions with the aim of improving general wellbeing and emotional health.

Wellbeing colleges

Some localities have well-being colleges as part of their commissioned services for mental health. The colleges are set up to offer a non-clinical, educational service to tackle areas such as anxiety, building self-confidence and anger management.

This approach aims to engage people in education and self-awareness for their mental health and well-being in a way that feels less clinical by personalising their care plan but picking courses that will aid their individual needs.

Routes to mental health services

Non-emergency:

You can self-refer via the primary care team (Also known as IAPTs) or your GP can refer to the Single Point of Entry/single Point of Access (SPOE/SPA). Where a practitioner will complete an assessment of mental state, risk and needs of the person. This will then lead either to a referral for the person to a suitable service within the NHS trust, or signposting for the person to go to an alternate service or provision.

Emergency:

If you feel unsafe from a mental or emotional aspect and you feel you are at a risk to yourself or to others, or you feel at risk from others you can attend your local A&E for an emergency assessment. You will be triaged and checked that you are not physically unwell. After that you will be seen by a Mental Health Professional who will assess your mental state and risk.

Dependent on the risks presented they may refer you to tertiary services (inpatients) or an alternative service in the NHS trust. Again they may also signpost to an alternate service or provision.

Safety Planning

If there are times when you feel unsafe due to mental health concerns and this is happening more frequently then you may need to think about safety planning.
Safety planning is around thinking about what might help in preparation for times of crisis. This may include having useful phone numbers or people who you can communicate with. It may also include distractions or interventions that might help such as favourite activities and tasks that will help to keep you from thinking about things that may trigger low mood. It may also contain favourite films, music or books that may help to improve your mood.

Stepped Care

Step 1:

- **Recognition:** Usually by GP or Practice nurse (Acknowledgment of problem)
- Involves: Watchful waiting, signposting for self-help (using appropriate resources)
- Checking in: Keep an eye on person, make sure they know they can get support

Step 2

- **Mild depression and/or anxiety:** Delivered by the Primary Care Team (PCT) in the person's locality or self-guided work via the internet
- May involve same stages as step one but more proactively by the PCT in the person's locality or self-guided work via the internet
- They will do a telephone consultation to work out what is going on and how best to support the person

Step 3

- **Moderate or severe depression:** Delivered by the PCT in the person's locality
- PCT will look at short term intervention (signposting up to secondary care services via SPOE/SPA)
- May include looking at a therapy intervention alongside a medication intervention

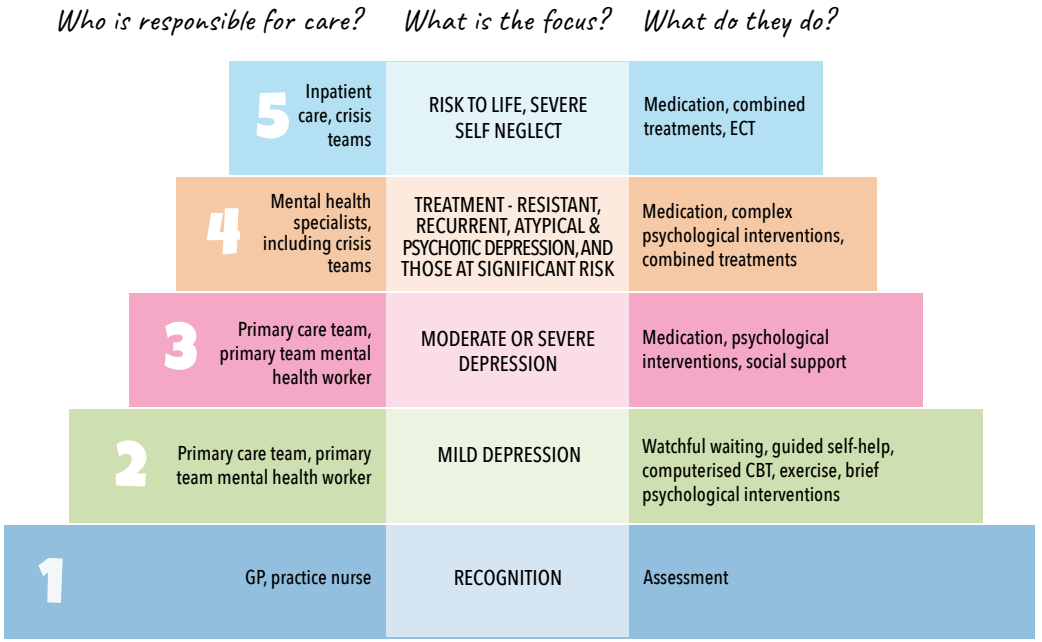
Step 4

- **Significant risks, recurrent severe depression, and psychotic illness, treatment resistant:** Delivered by secondary care mental health specialists, including crisis teams
- SPOE/SPA team will complete an assessment and look at the best place for onward referral for medium to long term intervention. (e.g. community mental health team (CMHT), to the early intervention team (EIT) or to a specific therapeutic intervention)

Step 5

- **Risk to life, risk to others life, severe self-neglect:** Medication, combined medication and psychological support: Delivered by the Crisis teams and/or inpatient tertiary services
- Intensive treatment at home and/or an admission to a mental health ward which can be as a voluntary patient or under detention using the mental health act
- Possible admission to hospital for any length of time depending on the assessment and care plan

This model of care is designed to be for people to move up and down. Some people may enter mental health services at step 1 and move all the way through to step five. Some may never leave step one. Some may enter at step five and leave at this level after a short intervention. Some may need more intense intervention and then some times only need their GP. The flexibility is there to offer support when it is needed. Model may vary but most NHS trusts use an equivalent



A list of services and names explained

CMHT: Community Mental Health Team. A team that offers longer term interventions to people who need support (consultant psychiatrist, nurses, social workers and allied health professionals)

EIT: Early Intervention Team. EIT, work with people experiencing their first episode of suspected psychosis. Primarily an assessment process and if the person is assessed as psychotic the team will work with them for a period of time. If not they will refer back to other services

IAPT: Improving access to psychological therapies. This is a model of care that most primary care teams use. It involves short periods of time with usually 6-8 sessions looking at a therapeutic intervention such as talking therapies. People are encouraged to self-refer to the service to promote self-responsibility

Primary care: This is the first point of mental health services which includes IAPT services. The team will offer short term interventions to service users and work with low risks

SPOE/SPA: Single Point Of Entry/Single Point of Access, this is the gateway between primary and secondary services. There is usually a team also sometimes called the access team. They will complete an assessment to look at which service is best placed for the individual. They may refer up into secondary or tertiary care or down into primary care

Secondary care: This is where the EIT and CMHT are in the stepped care model. This area of service involves medium to long term care interventions. Sometimes with a psychiatrist overview, it will also include learning disability services, memory clinics and home treatment/crisis teams

Tertiary care: Tertiary care is inpatient care and the crisis teams do overlap between secondary and tertiary care. Inpatient services are acute admissions wards for people who are presenting with significant risks to themselves or others. They may be admitted informally or under section. There are more specialist inpatient services depending on age (CAMHS and older people's services) or needs (forensic services for mentally disordered offenders, drug and alcohol services and eating disorders)

Crisis: The crisis team or Home treatment team aim to keep people out of hospital by offering a more intensive support such as weekends and evenings for a short period of time. They may also be available for support after discharge

CBT: Cognitive Behavioural Therapy

CAT: Cognitive Analytical Therapy

DBT: Dialectical Behavioural Therapy

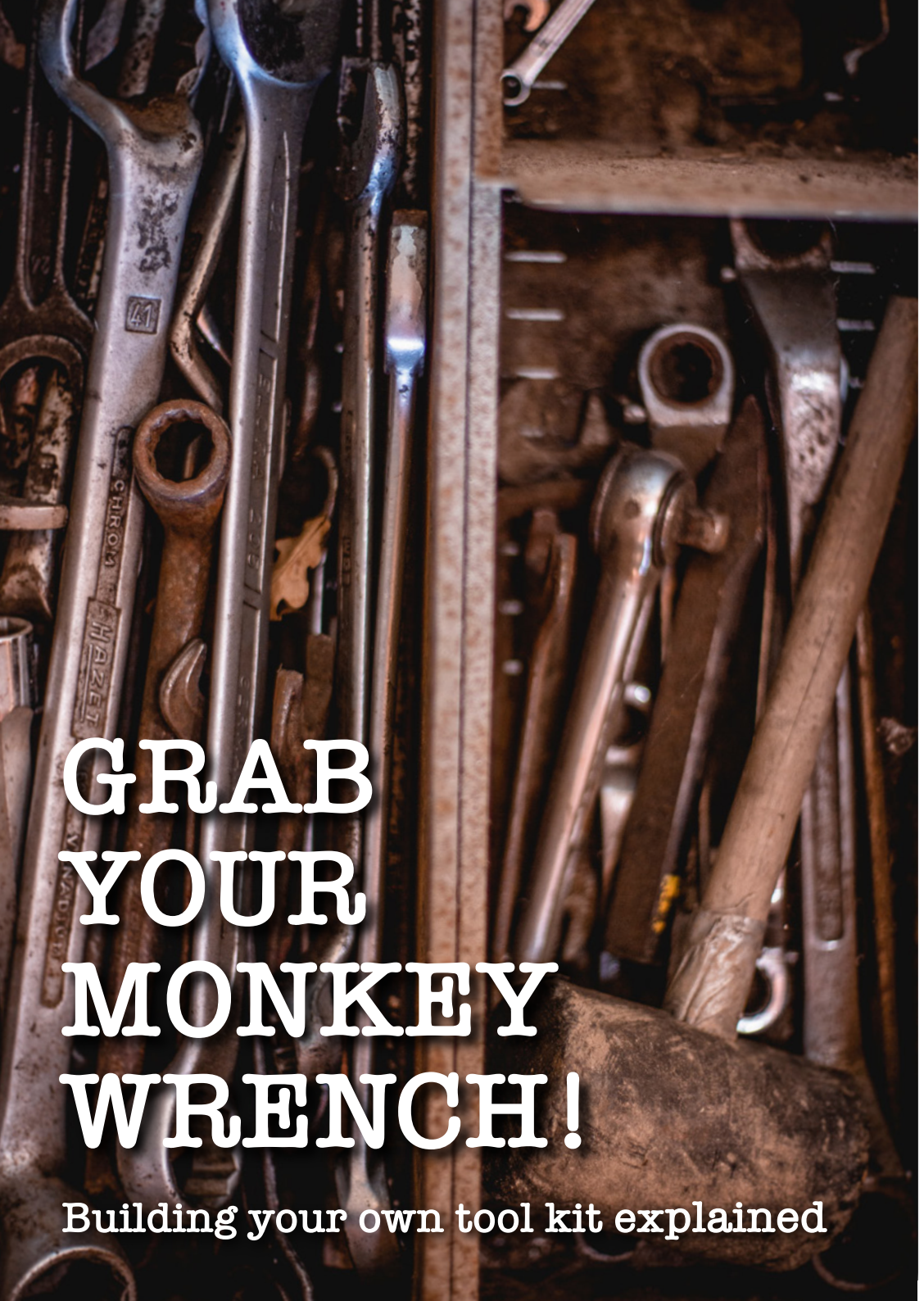
Informal: you have agreed voluntarily to attend hospital as an inpatient for assessment and/or treatment

Detained/Sectioned: You are being kept in hospital against your wishes under the legal framework of the Mental Health Act (1983). Depending on the section of the mental health act you are being held under you may be held for assessment and/or treatment

REMEMBER:

Genetic Counselling is something different, not to be confused with mental health counselling.

Genetic counselling is a communication process with patients that involves discussing the chance of inherited conditions, helping patients to make informed choices about genetic testing and reproductive options, and providing support at a time that can be stressful and highly emotional.



GRAB YOUR MONKEY WRENCH!

Building your own tool kit explained

The idea of a tool kit is one I have learnt from my own counselling sessions and training.

A tool kit is exactly what it sounds like. It is an imaginary tool kit, where I will find a number of ways to help myself when I feel low or when I get stuck in a rut or become frustrated due to Pompe.

Things that should be in the tool kit are little tasks and challenges that help you distract your mind, build resilience or help you feel calm. These could be anything from sayings or slogans that mean something to you, mindful exercises, creative fun or peace and tranquillity in nature. Whatever works for you is good to add to your tool kit.

This tool kit may take some time to build, and you may like to keep these things in your head to remember. I find that writing these things down on my phone or on paper helps, so I won't forget them for when I need them. When I am feeling stuck I go to my tool kit and challenge myself to do something from that list.

My Tool Kit:

- ✓ **Something to keep my mind focused when I feel anxious** – Reading or listening to calm music, using a meditation app or doing a mindfulness technique like a body scan.
- ✓ **Something for when I am feeling low and sad** – Watch some TV or film, go to bed early but most importantly remember be kind to myself!
- ✓ **Something to fill me with Joy** – going outside for a scoot, watching wildlife, speaking to friends (or when not in lock down - going out with friends), camping, campfires, watching the sunset.
- ✓ **Something mindful to fill an empty day** – Play with clay, try to draw something, cook up a feast and eat most of it.

Read Ben's story on page 44

Ben Parker

Visiting the DIY shop

Kit bag ideas

We have gathered together the 'tools' offered from the perspectives and experiences of other people living with Pompe. They shared them freely, thank you everyone.

"Be kind to yourself. If you feel tired then rest and take a Pompe Day. Other people think nothing of having a duvet day, sitting around in PJs and watching TV all day. Don't feel guilty if you need a rest day, or as I call them a Pompe Day".

"Embrace Pompe! We can't change what has happened, but we can change how we see things. I conserve energy wherever possible by using as many aids as possible for all the mundane tasks that I have to do to get through a day. This leaves energy to do things I want to do and helps to improve my quality of life. It also means that I'm able to do more and therefore my family and friends get to do more with me".

"Try to recognise your negative or bad habits and how they escalate when you are feeling low such as drinking, smoking, sleeping or eating too much".

"Acknowledge that it is ok to feel sad or frightened and that it's ok to feel happy. We have a range of emotions and all of them make up who we are".

"Accepting loss will be a valuable lesson when facing a life with Pompe disease".

"This is my favourite saying, 'Worry is like a rocking chair, it gives you something to do but never gets you anywhere' - by Irma Bombeck".

"Learning to say no when your body is telling you to rest".

"It is not being happy that makes you thankful, it is being thankful that makes you happy".

"As a general philosophy sort of thing I tend to say to myself 'look up not down'. I look at how to pass or go round a problem rather than letting it stop me or get me down".

"To realise that there are other people worse off than oneself is an important lesson to learn, at times this can be hard but an invaluable thought when it is needed".

"I often find that it's a matter of adjusting my perspective slightly! I've learnt that by focusing more on the 'small things', so often overlooked in life, helps me to derive the greatest pleasure to create a sense of positivity".

"Allowing time for you to do whatever you want and need".

Practical Ideas

"Eat as sensibly as possible, but enjoy your food and don't tire yourself preparing it. Never let yourself become over hungry or thirsty. Remember your brain needs to be fed so it can continue to work. If you don't feed the brain then it can affect our physical and mental state".

"One thing that really helps my mental health is watching trashy TV. I love completely rubbish shows such as married at first sight".

"Write down memories of a good day or a good event and then when you are having a bad day, pick one out. It really helps to remind you of something better, so you know a better day is coming soon".

"I look at other people's experience and theories such as the spoon theory. Look up techniques used by other people who suffer from chronic illnesses".

"Volunteer or just help someone else. I find I become very self-focussed and my thoughts go round and round in my mind. When I turn outwards to others it really helps me see the bigger picture. A phone call to a friend in need or perhaps do something more regular. Everyone has something they can give to others".

"A lot of the information we have needed to deal with in this pandemic has been very difficult to cope with. It is hard to stay calm and not let it work us up. I cope with this by, mentally quickly accessing, whether there is anything that I can do to help the situation.

As I am religious, if I cannot do anything tangible to help, I can offer up a prayer and put it to the back of my mind at that time, to be reconsidered in the future. *(Please note: you do not have to be a member of a faith community to pray)*. If prayer does not do anything for you, then meditate. Think about a situation but remember to 'let it go' if you cannot actually help, as too many such problems damage our own mental health".

"Finding something you enjoy and sticking to it".

"I am very thankful that I don't really suffer with my mental health. The one thing I try and do every day is go out for a walk (a roll in my case), grab a coffee and say good morning to as many people that I can as this lightens my mood and sets me up for the day".

"A SAD (Seasonal Adjustment Disorder) lamp improves, sleep, focus, energy and moods, especially during winter days".

"A hobby or interest works for me. I enjoy modeling and making dioramas. It takes me back to my childhood as well".

"Learn an instrument. You don't have to be any good or to have done it before. Pick up a second hand one locally or from an auction site and give it a go. If you get on with it, then you can buy better".

"Try and get outside every day, even if it means just opening a window. Fresh air is good for our minds and body".

"Remember to look after yourself, be kind to yourself and relax as much as possible".

"I genuinely believe that routine and exercise play an important role in helping to maintain good mental health. Even if all you can do is tap your fingers, turn your wrists or move your head from side to side. What's important is trying and not waiting for things to get worse! I find that a regular routine is the best way. I try to live by the rule 'Use it or lose it'. I do the 20 minute HAS FIT sitting exercises for seniors most days on YouTube, (not using hand weights). I modify some exercises to suit my physical condition. I also do 2 other 20 minute routines in bed at night and in the morning, using wide rubber bands to exercise my legs and small weights for my arms. I have found that ECCO shoes and sandals are very comfortable, reasonably lightweight, and non-slip".

"I love audio books and I try to use my mindfulness apps".

"Speak to your specialist centres about tailoring the exercises you are given to suit you. Not all generic exercises work for us individually".

More Practical Ideas

"Try and achieve things that will help you feel like you have accomplished something. Whether that be washing up, reading a chapter of a book, drawing a cat or finally moving that wire that you are always frightened of tripping over".

"Find a local or online Pilates, Yoga or Personal Trainer. Exercises and stretches can be adapted to our needs making us feel we can accomplish some physical exertion".

"A dog! We had two, both boxers, which have a lovely temperament, and are either juvenile or senile! They are very good natured, love playing, great companions and very therapeutic. 10 minutes spent stroking them and you're totally de-stressed".

"I do not have enough energy for the day and have to plan my week very carefully to ensure I don't do too much on any one day. Even phone calls or emails are tiring and I find it difficult to concentrate for long periods, particularly later in the day. I have a 'cut off' point, after which I will just do what I want to and relax".

"I like to go online and read messages from other people I know. Sometimes this really helps me and I get a lot from sharing but I know Facebook does not appeal to everyone".

"A monthly massage helps to make my pains a bit easier to cope with which in turn helps my mood and mental health".

"I'm sure we all have pictures or objects around the house with good memories and associations. For instance we've bought quite a bit of art that we like, but could also be photo albums, pictures of family or whatever. Make a conscious effort to look at at least one of them every day and hopefully get a glow of positivity from either a memory or that you've got something nice to look at".

"Challenge yourself to achieve small tasks. You are not going to change things instantly, remember that small steps are the only way to change. I write a list on my phone which I always add to or delete once achieved. This way I feel like I am making progress, no matter how small".

"Try to stick to a routine as much as you can. Wash and freshen up, the small things add up to make a bigger brighter picture".

"Keep busy with distractions such as creating, crafting, drawing, journaling and try something new now and again. You may just find out you like it".

"Having two cats on my lap helps me to feel calm".

"To put your energy into helping others, it seems to relieve one's own moments of inner dwellings".

"Keep up with physical exercising and stretching routines. It is proven that daily exercise, even if for a small amount of time, can help our metal health. But make sure you listen to your body when you need to rest".

"Remember that there are Pompe patients out there that have most probably felt and feel the way you do. If you feel brave enough, ask them on the Facebook groups, or email and speak to them privately. We may not have any answers but it will feel good to offload with someone that understands".

"Being able to talk to someone who truly understands my problems really helps. This is usually another Pompe patient. Close friends, family and even trained professionals may be able to help and listen but no one really 'gets it' and understands how I feel and what I have to go through on a daily basis like another Pompe person does".

"When I speak to my Pompe friends it always gives me hope that whatever happens I will somehow find a way of coping".

"We don't always have to push ourselves. Allow periods of rest and recovery to charge the batteries or '*gather the spoons*'".

Therapeutic Ideas

"Write down three things that you are grateful for every day. At the beginning I found this really hard, but now I do it every day and always find it works for me. I was advised this by my counsellor".

"Being able to talk to someone is very important".

"Meditation for me is a massive help, particularly at bedtime it helps me get off to sleep much easier. It helps me to collate my thoughts and stop intrusive thoughts and I find I drift off easer. It helped me a lot with my anxiety at the beginning of lockdown too. It changed my outlook at the beginning of the day. I use the CALM app. There are lots of people on there with experience who offer stories and all sorts of options. They talk you through a step by step guide to help you to learn how to meditate at the beginning as well".

"Remember, for anyone who is working, sometimes for family members as well, there are often work place counselling services. They are mostly confidential and mostly free too. They can be a really useful resource".

"Remember that thoughts are just thoughts. They aren't reality and they are often irrational and unkind".

"Make sure your internal speech is positive and talk nicely to yourself. If you drop something or slip or stumble, speak to yourself as if you are someone else being kind. If you were talking to someone else you would be encouraging and nice. So do this for yourself. This was from my psychologist at Addenbrookes. She also suggested using a soft voice e.g. If I break a glass I used to say 'oh you silly thing, you should not have tried to do that when you were tired'. Now I say, in a soft voice, 'don't worry, it's just a glass, you can clear it up easily and forget about it'".

"Be kind to ourselves, the largest, most powerful voice is the one inside of our heads. Treat yourself with the same respect we treat others".

"Research the different types of counselling therapies, as one may not necessarily work for the person you are. You have options such as CBT, Person Centred and Integrative".

"Talk to your GP about antidepressants, don't be embarrassed. It can be due to a chemical imbalance, just like not producing an enzyme with Pompe. Depression can act in the same way. There is nothing wrong in taking tablets to help you feel better".

"The best thing someone said to me was 'You are not your thoughts'. When my thinking gets overwhelming and not peaceful I remember that my thoughts are separate to my life".

"Body scanning helps me. I was taught by a physiotherapist but it is easy. Take some moments to focus on your own body starting from your head or feet. Think about each area and release tension from it, then move on to the next and do the same. It is relaxing and distracting".

"One of my favourite things is my yoga class which we've carried on over zoom throughout the pandemic. It serves a number of purposes in that it makes me feel good that I'm trying to exercise but it's also a good social outlet as I've been doing the same class for 9 years so it's a good group of friends. Pompe means I am not the best at yoga but I have a wonderful teacher who adapts all the exercises and I never feel like the odd one out".

"Speak to your specialist centres about accessing counselling, psychotherapy or physical therapy".

"When I have anxiety I use 7-11 breathing. This way I breathe out more than I breathe in. Breathe in and count up to 5 or 7 or whatever. Then breathe out, (normally) but just for a little bit longer than you breathed in".

"Ask to see a counsellor through your local GP. If you can afford it and can't get face to face access through your GP, pay to see one yourself".

Parents & Carers

Caring for a child with Pompe disease brings with it a different set of challenges and joys. Here are ideas from parents in our community:

"I think that to talk to someone that understands how you feel can help".

It very hard because my child is badly affected, I've come to terms that he will never walk, Pompe is so variable and I see other affected children running and walking, I have grieved but now know that he has his own amazing life in his own way and I do not make comparisons".

"I think you have to keep everything in perspective. Accept the diagnosis, accept it is progressive, make the most of everyday and be thankful for it. As the condition progresses, you have to accept this as the new normal. This mindset has made it easier for us and we can cushion the blows a bit".

"Talking to other Pompe families has definitely helped us in our journey".

"My children like to educate their classes in Pompe in general. It helps to give them a voice".

"It's so isolating to begin with and you feel like no one understands".

"It is isolating now even though I talk to other Pompe families because trying to describe and get someone to understand Pompe is a battle within itself".

The word hospice feels frightening, but when we actually connected to them we found love, support and loads of activities and meetings for the family"

"There are Facebook groups for parents and another one for carers. This could be a good point to start".

"You also have to have time for your other children, not just your child with Pompe. They also need to process what is happening".

In 2018, Care Advisor, Jane Lewthwaite held a carers discussion workshop. It is worth sharing what we gathered:

Feelings about being a carer

- Patronising information and suggestions
- Crisis
- Feeling out of control
- Cannot fix it
- Grieving for a life we thought we would have
- Overlooked
- In the background
- Loving
- Caring
- Lack of time
- Caring for someone who doesn't want it
- Powerlessness
- Guilt for not doing more
- Guilt for doing something for myself

"I feel I've taken my husband's freedom away and the kids have to help mum far more than their friends do".

Suggestions from my experiences

- Counselling can help
- Don't plan too far ahead
- Make gradual changes
- Ensure GP knows you are a carer
- Learn about the condition
- Acceptance
- Stay well informed
- Meeting others
- Know the person is still a person
- Join a carers group
- Get a Lasting Power of Attorney, especially if you are not married

Websites

- www.carersuk.org
- www.gov.uk/carers-uk
- www.carers.org
- www.ageuk.org.uk
- www.carerssupport.org.uk
- www.musculardystrophyuk.org
- www.carersclub.org

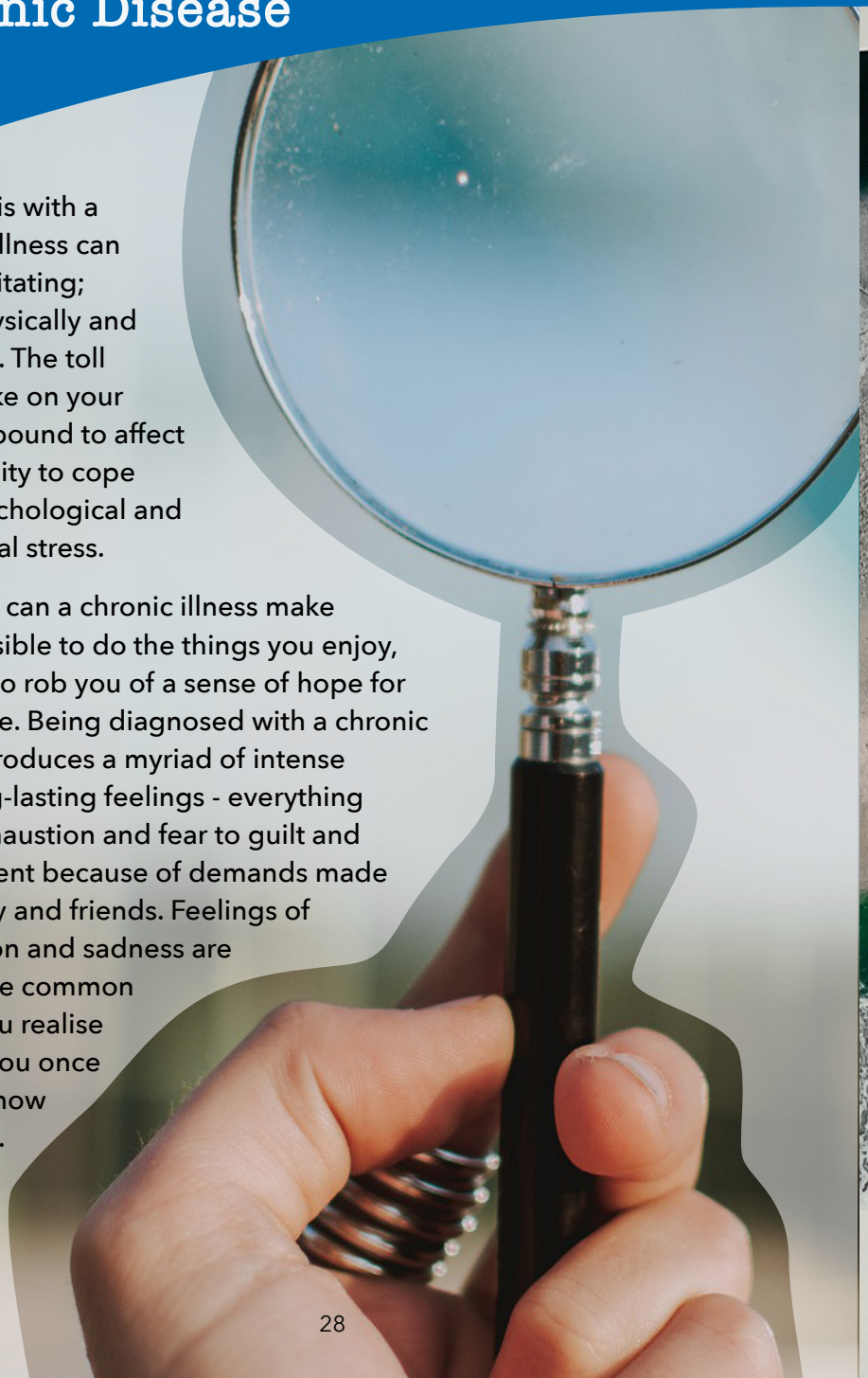
Local

- Search for Carers Support Meetings
- Social Services Help Desk – phone to request someone to review your needs (a carers assessment) and ask them to tell you what is available
- Register as a Carer with your GP

Benefits Advice

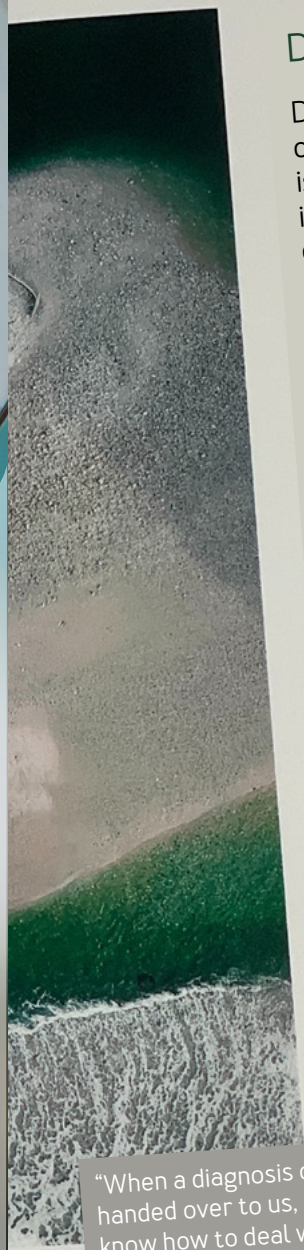
- Phone your Citizens Advice Bureau, local Carer's Organisation or local Disability Organisation and ask for an appointment for a full benefits check.
- Contact AGSD UK for supporting letters and advice on completing the forms

Diagnosis with a Chronic Disease



Diagnosis with a chronic illness can be debilitating; both physically and mentally. The toll it can take on your body is bound to affect your ability to cope with psychological and emotional stress.

Not only can a chronic illness make it impossible to do the things you enjoy, it can also rob you of a sense of hope for the future. Being diagnosed with a chronic illness produces a myriad of intense and long-lasting feelings - everything from exhaustion and fear to guilt and resentment because of demands made on family and friends. Feelings of frustration and sadness are also quite common when you realise the life you once knew is now different.



Depression & Chronic Illness

Depression is one of the most common complications of chronic illness. It is estimated that up to one third of individuals with a serious medical condition experience symptoms of depression.

According to the USA National Institute of Mental Health (NIMH), people with chronic medical conditions have a higher risk of depression, and they tend to have more severe symptoms of both illnesses. This has prompted many professionals to recommend a patient be treated for both the depression and the medical illness at the same time.

Finding out you have a chronic illness may exacerbate the symptoms of a pre-existing mental health condition like depression. Julie Barthels, MEd, MSSW, LCSW, says some of the factors that influence symptoms of depression include physical pain of the illness, the grieving process of losses associated with the illness, the fear of "what it is", and a sense of hopelessness that life will never get better.

Source Sara Lindberg BSc (Hons), MSc (2017)

https://patient.info/news-and-features/how-a-chronic-illness-affects-your-mental-health

"When a diagnosis of Pompe is handed over to us, none of us know how to deal with it, there is no guide book, there is just this fact your own thoughts and your own emotional reaction to it".

"A lot of people I know living with Pompe are prescribed anti-depressants. There is no shame in this. Pompe can feel like a load or burden that I live with and manage day to day".

Living with loss & Pompe disease

There are many kinds of loss and living with a degenerative muscle disease is one of them.

Louise Halling has a muscle condition not dissimilar to Pompe disease [Limb Girdle Muscular Dystrophy] and is a trained counsellor; she writes

"When we lose someone we love, we wouldn't hesitate to consider having grief counselling. So why should the loss of muscle function and independence be any different?

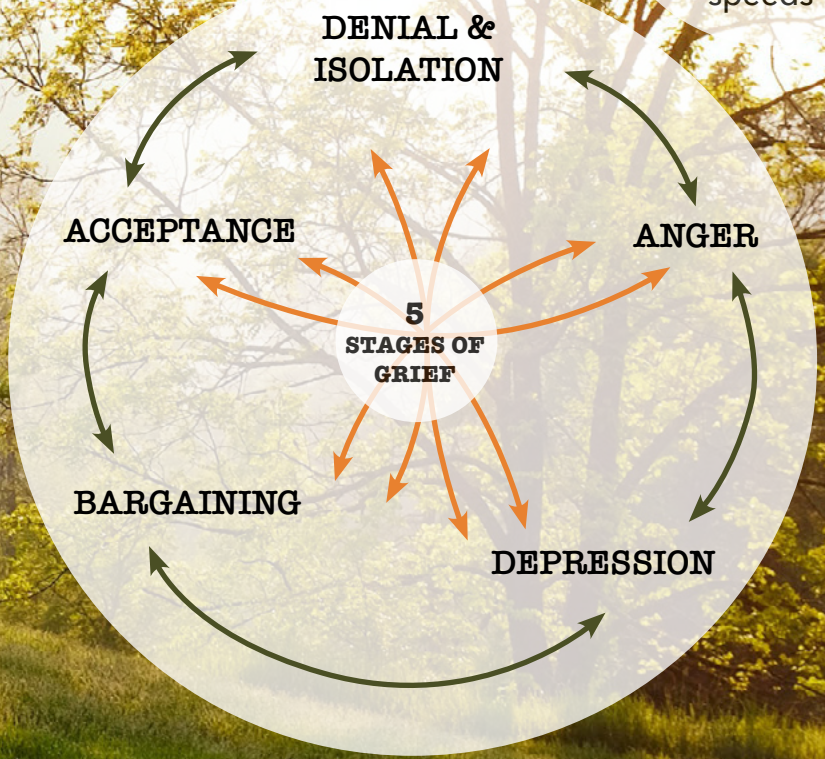
The key for psychological support must be to recognise that for many people with muscle-wasting conditions – regardless of the circumstances – this is a journey of loss".

(Ref: MDUK website 2021)

"It took me years to come to terms with my diagnosis. Firstly, I felt relief and vindication, then despair, then elation when I had good test results. It is an emotional roller coaster but I decided that I am in control of how I feel and how I cope, so I feel much better now".

"Allow the grief to take place, give yourself time to grieve and adjust".

"Coping is very personal. Everyone grieves in their own way and at different speeds".



Elisabeth Kübler-Ross [1969] introduced her five stages of grief: denial, anger, bargaining, depression, and acceptance. These do not really run sequentially one after the other. People move in and out of the stages over a long period and sometimes are in more than one stage at a time. Coming to terms with a muscle condition also often causes feelings like this, as in the illustration opposite.

Therapy for people with muscle-wasting conditions?

Acceptance and Commitment Therapy (ACT) encourages people to embrace their thoughts and feelings rather than fighting or feeling guilty for them. It may seem confusing at first, but ACT paired with mindfulness-based therapy offers clinically effective treatment.

There is currently a research project underway (called ACTMuS) lead by ***Dr Chris Graham*** of Kings College London to examine the effectiveness of acceptance and commitment therapy for people with muscle-wasting conditions. ACT has already proven effective for people with cancer and other long-term conditions, such as multiple sclerosis.

It is designed to help accept a change in your life that you cannot control. The results are not yet available from the study. ***Sara Lindberg*** offers more useful advice:

Ways to cope: Forging a new life with a chronic illness is a challenge. And it's quite common (and normal) to feel fear and sadness as you make sense of your diagnosis. But as you begin to formulate a plan for living, it's important to understand that you're not alone. This is a time of healing - and you must surround yourself with those things and people that make you feel good.

Stay connected to healthcare professionals
It's important to establish relationships with the medical experts who are assisting you through this process. Being able to talk openly about your ongoing questions and concerns will arm you with the knowledge about your illness and help you feel more settled.

Surround yourself with support: Life with a chronic illness can feel lonely. Isolation, mental health issues, and physical restrictions all make it difficult to connect with other people and get the support you need. That's why it's essential to surround yourself with support, including your personal support system and professional support. We are fortunate to be able to have so much information and support available to us online - especially for the chronically ill, many of whom have a hard time getting out of their homes, or find that getting out is impossible.

Physical and mental self-care: Both mental illness and chronic health conditions do best with a reduction of stress, improved sleep, and following the medical provider's recommendations for treatment. Diet changes and exercise can often lead to an overall improvement in the conditions.

Boom or Bust? Using Spoon Theory

by Amanda Porter (Article reprinted from Glisten newsletter March 2021)

Spoon Theory may help explain how your GSD affects you. If you have a GSD, perhaps even late-onset Pompe disease as I do, you might be dealing with muscle weakness, aches and cramps and fatigue. Many people may not understand how overwhelming this can be, and it may not always be easy to explain. However, an analogy called the spoon theory may help family and friends understand what you go through regularly. Spoon theory was conceived by lupus patient, Christine Miserandino.

What is Spoon Theory?

Energy, for most of us with a chronic illness, is limited and depends on many factors including stress levels, how we're sleeping and pain. According to the theory, you start each day with 12 theoretical spoons. You have to give up one spoon for each task you perform: brushing your teeth, putting on clothes, visiting the doctor, making dinner etc. When you finish using all the spoons, that's it. You are done for the day!

Healthy people have all the energy necessary to do whatever they need to do in a given day. Spoon theory illustrates how those with a chronic disease, as well as their caregivers, have a finite amount of energy that must be carefully rationed. Performing one errand or task can limit what you can do for the rest of the day. In the words of a Pompe patient: 'The main thing for me is that it helps explain to other people about why I have to plan ahead and think carefully about what I'm doing as I don't have the same amount of energy as they do".

How do I put the Spoon Theory into use?

Understanding that you have only so much energy renders daily prioritising and planning crucial. Show yourself compassion if you don't complete everything you set out to do. When you've spent all your energy, you are done for the day.

The guilt associated with having a chronic illness is a heavy burden. One of the things the Spoon Theory can help with is that separation between what we'd like to do and what our illness dictates. Practicing self-care is vital. You know your body and needs best. When you've exhausted your spoon set, ask for help from others.

"Working as a Care Advisor for people living with Pompe disease, it seems to me some people adapt and adjust to living a carefully managed lifestyle and they seem to stay on a more even keel. Living in a 'boom and bust' relationship with Pompe leads to greater physical and mental pain".

Conference Notes on Mental Health

My Story: Anabel Rajgor

AGSD-UK Conference in 2017

My background

Professionally, I started my training as a Cognitive Behavioural Psychotherapist, or CBT, about 10 years ago, and I specialise in the more common mental health problems such as Depression and Anxiety" Disorders. CBT is rapidly being offered to more and more people across the country suffering with all sorts of psychological problems. This is through a government initiative, started a few years ago called IAPT or improving access to Psychological Therapies. IAPT is an NHS programme rolling out psychological services across England offering interventions approved by the National institute of Health and Clinical Excellence (NICE) for treating people with depression and anxiety disorders.

What this should mean, is that if you ask your GP for Psychological help, you should be offered an assessment, and in some cases, that can take only a few days. CBT is being offered as an alternative to medication or used alongside medication depending on the need. It's a fantastic service of which I've very proud of being part of.

CBT isn't for everyone and it isn't a miracle cure. It takes tremendous skill, strength and courage of behalf of a patient, to actively overcome their difficulties. But time and time again I'm humbled by the effectiveness of CBT, the determination of people to help themselves and the improvement in people's day to day lives. If CBT, or other therapies within primary care aren't suitable, then patients can be referred to secondary or specialist services for further care.

Depression

Depression is a genuine health condition. It's not all in the mind. It often needs treatment from a professional and often it doesn't just always go away on its own. It is the leading cause of disability worldwide, and is a major contributor to the overall global burden of other diseases. For a diagnosis of Depression, core symptoms, must occur consistently over a minimum of two weeks. These

symptoms include reduced pleasure and interest in everyday life, persistent low mood, reduced energy and reduced activity. Problems with sleep, reduced appetite, increase irritability, reduced self-esteem, feelings of worthlessness, powerlessness and hopelessness.

Triggers for depression can often involve:

- Significant losses in a person's life (Bereavement, good health, relationship ending)
- Major life transitions (Having a baby, changing jobs, retirement)
- Relationship disputes (Partners, employers)
- Role changes (Becoming a parent or a care-giver)
- Prolonged periods of stress and anxiety (Bullying at work)

I'll try to explain these triggering factors through my own experience.

The diagnosis of Pompe for me, like many of us here, took a while. I would often see my GP for pain, but not for muscle weakness. At the time and growing up, I didn't realise my body was weaker than other people's; I just thought I was unfit. When the testing got a little more serious, you'd often here me speak about feeling like a piece of meat. What I meant was, I felt I wasn't being treated holistically like the complex human being I was. Health professionals, lovely and highly skilled, as they were, were only interested in their specific area of testing; no one really asked me how I felt. Until I met my specialist team in Cambridge who then directed me to AGSD-UK.

But for all those years the effect of ongoing pain, weakness and uncertainty were taking their toll on me. I was working in London, and I couldn't keep up with friends going out and partying, I'd get frustrated, I couldn't get up and down the stairs on the tubes. I felt exhausted, every day struggling to develop my career and be competitive. So here we have some of those key triggers for depression.

When I was diagnosed with Pompe on some level I felt relieved after many years of not knowing what was wrong with me, but there was also a tremendous sadness and despair, at the sense of loss I felt. I would never run a marathon for example, I mean, not that that was ever one of my goals in life, and it might sound trite, but to have those sorts of choices taken away was brutal. I felt weird, weak and vulnerable. It was also a role transition. I now saw myself as a disabled person, and all the stigma and discrimination people with

disabilities face today was now going to be directed at me. I had to adapt to dealing with the fact that in my late 20's I needed a walking stick when out on my own. I needed hand rails, flat unsexy supportive shoes, lifts, raised toilets, radar keys, grab rails, an automatic car, etc.

I grieved, I got angry, I cried, I ignored it, I got depressed, I faced it, and eventually I worked through it.

These things helped:

1. Family, friends and my husband were the most important
2. Homecare team and specialist doctor
3. AGSD–UK

But ultimately it was down to me. I never like to be told I can't do something. If Pompe said I couldn't go travelling. B***er that, I was going travelling! I developed my career, I got married and had a beautiful baby daughter and son. If I couldn't ride a bike, I'd buy an electric one. I wouldn't be beaten. I realised I had to make adjustments to have equal access to things other people took for granted. Travelling: we planned mobility issues, which basically involved my husband carrying everything! Career: I moved back home and reduced my time at work. In this case having a supportive boss was essential. Having a baby: well, that's an ongoing "make it up as we go along" strategy!

Being a therapist also meant that I had some of the skills and insight to help me work through some of my low mood and anxieties. When I felt anxious about what people would think of me with a walking stick, I went out to find out. I tested my assumptions. And in fact, I found most people were fantastic, they moved out my way because now they had a visual cue that I struggled a bit more. I was less bitter about the world. I could see that having a disability, and struggling emotionally with the diagnosis and management of it was not a weakness; it was normal, in fact it was a sign of my strength.

Counselling

I also sought help from a professional counsellor. In a safe place I could fully explore without judgment and shame all the things I was feeling. I felt that the Pompe was taking over my life. My mobility everywhere, my diet, my career, my relationships and my future. But I learnt that I was a person who now lived with a long term condition, I wasn't that condition.

Depression means that its harder to do things, even like getting out of bed is a milestone for some people, So finding the motivation to do some light muscle strengthening exercise is a long way off. People with depression often don't eat well, reduced energy and activity can mean eating more convenience food or snacking or high carb or sugary foods, people may go out less due to Mental Health and Wellbeing anxieties about mobility issue or social stigma.

There are new challenges I face now. That grieving process isn't linear, its messy. I still have times when I get angry and anxious. I feel sad when I struggle to do something or something is taken away, but I remind myself that Pompe and my experience of depression has given me something. For me, it's given me a deeper understanding of what it is to be human. "To err is to human". We're not perfect, we're not all the same. I totally get that and I'm more comfortable in my own skin. I've developed a better understanding of myself and what it means to be human.

If you are concerned about your own, or someone else's mental wellbeing: Talk about it.

- Seek help from friends, family, GP.
- Research online about CBT and mental health.
- Look after your basic wellbeing - eat well, sleep well, exercise, socialise, get a hobby, do something for other people, these are all good for our mental health. Mental health first aid!
- Go and see your GP, if they're not very psychologically minded, find another GP.
- Collect some leaflets for your local NHS IAPT services to hand out, or just ask people how they're coping with it all.

Where to find help:

- AGSD–UK website and Glisten newsletter
- IAPT website (see below)
- Mobile apps
- Private CBT - BABCP website
- Books ("I Had a Black Dog" by Matthew Johnstone "Overcoming Depression" by Paul Gilbert. Audio CD version also available)

Websites:

- NHS Improving Access to Psychological Therapies (IAPT) programme
- www.england.nhs.uk/mental-health/adults/iapt
- British Association for Behavioural and Cognitive Psychotherapies www.babcp.com
- Living Life to The Full www.llttf.com

Notes from the AGSD-UK Conference Roundtable on Mental Health

October 2019

By Tracey McGrae, Clinical Nurse Specialist

Carers: are there services for them?

Local authorities can offer support/respite for young carers and siblings of young patients. They can access local hospice care too, which often have events and activities.

Raising awareness of Pompe and mental health:

Reducing the stigma generally around mental health, how does a society do this? Social media was mentioned and considered as a peer support group online or on social media.

Routine and structure

These are ssential to mental well-being and differing levels of motivation to engage in this. We agreed this was dependent on where people are in their journeys with their mental well-being. This led onto us talking about the stages of change.

Bereavement

Adapting to things and considered the stages of bereavement in how you will continuously have losses as the illness progresses and this is a constant adapting process which can be impossible at times. In the theme of adapting we also spoke about adapting to things as Pompe progresses such as not going out in the snow. We agreed that this is a reasonable adjustment to the illness to minimise the risks that may be around lower mobility.

Practical planning

This is a necessity due to changes in mobility, without making this about anxiety and recognising the differences between learning to adapt versus illness behaviours. Make a list of pros and cons lists of what is an irrational thought that might reflect more on your mental state versus what is a rational though in this context.

Prochaska and DiClemente's (1983) Stages of Change Model

This model describes five stages that people go through on their way to change: Precontemplation, contemplation, preparation, action, and maintenance.

The cycle of change is a good tool to assess someone's readiness to engage and how a rapport and time to get to know someone is also essential. This led onto a discussion about how to get this in a service.

We all acknowledged that sometimes accessing generic mental health services is not as helpful as it could be as they don't know about Pompe and its complications.

Support

Sources of support & further information

Local NHS – Every Mind Matters

https://tinyurl.com/yeujlfnq

Long-term physical conditions and mental health

https://www.mentalhealth.org.uk/a-to-z/l/long-term-physical-conditions-and-mental-health

Coping with physical illness

https://www.rcpsych.ac.uk/mental-health/problems-disorders/physical-illness

Suicidal Feelings

https://www.time-to-change.org.uk/about-mental-health/types-problems/suicidal-feelings

Depression

https://www.time-to-change.org.uk/about-mental-health/types-problems/depression

Anxiety and Panic attacks

https://www.time-to-change.org.uk/about-mental-health/types-problems/anxiety-disorders

Podcasts and videos

https://www.mentalhealth.org.uk/podcasts-and-videos

Looking after ourselves

https://www.mentalhealth.org.uk/your-mental-health/looking-after-your-mental-health

Samaritans

Telephone: 116 123 (24 hours a day, free to call)

Email: jo@samaritans.org

Website: https://www.samaritans.org/

The Samaritans provide confidential, non-judgemental emotional support for people experiencing feelings of distress or despair, including those that could lead to suicide. You can phone, email, write a letter or in most cases talk to someone face to face.

Mind Infoline

Telephone: 0300 123 3393 (9am-6pm Monday to Friday- except bank holidays)

Text: 86463

Email: info@mind.org.uk

Website: https://www.mind.org.uk/information-support/helplines

Mind provides confidential mental health information services.

With support and understanding, Mind enables people to make informed choices. The Infoline gives information on types of mental health problems, where to get help, drug treatments, alternative therapies and advocacy. Mind works in partnership with around 140 local Minds providing local mental health services.

Rethink Mental Illness Advice Line

Telephone: 0808 801 0525 (9.30am - 4pm Monday to Friday, free to call)

Email: advice@rethink.org

Website: http://www.rethink.org/about-us/our-mental-health-advice

They provide expert advice and information to people with mental health problems and those who care for them, as well as giving help to health professionals, employers and staff. Rethink also runs Rethink services and groups across England.

SANEline

Telephone: 0300 304 7000 (4:30pm-10:30pm 7 days a week)

Text: 07984 967 708

Email: support@sane.org.uk

Website: www.sane.org.uk

SANEline is a national out-of-hours mental health helpline providing information and support to people with mental health problems and those who support them.

The Mix

Telephone: 0808 808 4994 (3pm-12am 7 days a week, free to call)

Email: Helpline email form (on website)

Crisis Support: Text 'THEMIX' to 85258 (24/7 crisis support across the UK)

Website: www.themix.org.uk/get-support

The Mix provides judgement-free information and support to young people aged 13-25 on a range of issues including mental health problems. Young people can access The Mix's support via phone, email, webchat, peer to peer and counselling services.

ChildLine

Telephone: 0800 1111 (24 hours a day, free to call)

Website: www.childline.org.uk

ChildLine is a private and confidential service for children and young people up to the age of nineteen. You can contact a ChildLine counsellor for free about anything - no problem is too big or too small.

Elefriends

Website: http://elefriends.org.uk/

Elefriends is a supportive online community where you can be yourself. Elefriends is run by Mind.

If you're a carer needing support you can contact all of the above as well as Carers Direct and the Carers Trust, both of whom are able to provide support and advice on any issues affecting you.

SHOUT

Shout is the UK's first 24/7 text service, free on all major mobile networks, for anyone in crisis anytime, anywhere. It's a place to go if you're struggling to cope and you need immediate help.

Text: 85258 (24 hours a day, free to text)

Website: https://www.giveusashout.org

Highly Specialised Services for Lysosomal Storage Diseases

Paediatric Centres for IOPD and LOPD

LONDON	Great Ormond Street Hospital Department for Inherited Metabolic Disease
BIRMINGHAM	Hospital for Women and Children Centre for Inherited Metabolic Diseases
MANCHESTER	Royal Manchester Children's Hospital

Adult Centres

BIRMINGHAM	University Hospital Birmingham Queen Elizabeth Hospital Department of Inherited Metabolic Disorders
CAMBRIDGE	Addenbrookes Hospital Lysosomal Storage Disease Unit
LONDON	The National Hospital for Neurology and Neurosurgery Charles Dent Metabolic Unit
LONDON	The Royal Free Hospital Lysosomal Storage Disease Unit
MANCHESTER	Salford Royal The Mark Holland Metabolic Unit

National Centres

CARDIFF	University Hospital of Wales Inherited Metabolic Diseases Service
GLASGOW	Managed Clinic Network Inherited Metabolic Disorders Scotland
BELFAST	Belfast City Hospital Genetics Unit
DUBLIN	Children's University Hospital National Centre for Metabolic Disorders

As well as the Highly Specialised Services the John Walton Centre for Muscular Dystrophy Research Centre at the Centre for Life in Newcastle offers care for neuro-muscular conditions to those in the catchment area.

A Message from Ben

This is a not a booklet that provides every answer but I hope it has helped you find your own route to help yourself and shown you that you are not alone, that there is help out there, there are people who will listen to your problems and you can make changes to your life and make it a little less stressful and a lot brighter.

For those that don't know me, I too have Pompe. I was diagnosed 14 years ago at the age of 27.

I volunteer with AGSD-UK and I helped set up the PST (Pompe Support Team) about 8 years ago with a small group of patients, our main aim was to support other patients by bringing about awareness of our daily struggles of living with Pompe.

As a group we have written a collection of informative booklets and leaflets which are all available by emailing info@agsd.org.uk and on the AGSD-UK website, we also organise events and meet ups, support and speak up for the Pompe community in the UK via meetings with pharmaceuticals and governing health bodies, we contribute to each year's conference and bring up important issues that we feel need to be spoken about. So we like to keep ourselves busy.

I've personally been speaking up about mental health for a while now and for me it is an important part of coming to terms and trying to live with, and deal with, the effects of a long term health condition like Pompe.

It can be a lonely path we patients, parents, carers and family members are all on, and we all need some support at times, this is one of the main reasons behind my motivation to write this booklet, to try help others who feel in a similar place.

For some people, emotions can be a hard subject to discuss. Feelings are not talked about enough; we can bottle things up and carry on expecting everything to be okay. Sometimes that bottle can overflow and some of these hints, tips and information in this booklet will hopefully help you deal, understand or at the very least maybe put you on a path of self-discovery.

Part of staying healthy is being informed.

Use these publications; they are all good, created for people with Pompe, by people with Pompe.

Contact Information:
Telephone: 0300 123 2790
Email:info@agsd.org.uk
Facebook: @AGSDUK

Address:
AGSD-UK
PO Box 1232
Bristol
BS48 9DD

Registered Charity:
1132271

AGSD UK
Association for Glycogen Storage Disease