'My Needs'

HSE's National Guidelines on Accessible Health & Social Care Services 2014
https://www.hse.ie/eng/services/yourhealthservice/access/natguideaccessibleservices/natguideaccessibleservices.pdf

A reminder that I have the right to give informed consent.

No one is entitled to attempt to 'make' me do what I know harms me or exacerbates my symptoms.

Diagnosis: Myalgic Encephalomyelitis (ME), WHO Classification: ICD 10 G93.3 Neurological Disorder.

ME is a chronic multi system illness in which energy at cellular level is not created normally; the acts of daily living deplete my body far beyond what people understood as 'fatigue,' this energy depletion affects every system and organ in the body.

Exceeding my energy availability will result in a 'crash.' I will be weak and disorientated as the brain 'shuts off' non-essential physical and cognitive function in order that the remaining limited energy is available to the organs and systems essential for life. Overload phenomena is part of the complex pathophysiology of ME as the body reacts to sensory inputs which it does not have the energy to manage.

Post Exertional Neuroimmune Exhaustion (PENE) is the defining symptom of ME.

Exceeding my available energy, ('available energy' depends on how well I am), results in an exacerbation of symptoms. PENE can be caused by any 'activity' i.e. activities of daily living, speaking with someone, moving around the house, conducting essential business.

The aim is to establish an activity baseline & not exceed it

The 'baseline' is variable depending on many factors, my environment (temperature, light, noise), how much I have done in recent days, how well I am, attending a medical appointment, being required to communicate with people when less able, being forced to react, choosing to engage in activities which I enjoy etc.

Planning a month & at a minimum a week ahead is essential

I need to know what is happening in advance so that I can plan how to use my limited energy to best effect in order to have the best quality of life without exacerbating symptoms.

I need to be able to trust that those supporting me know how to care and support me so they do not cause me harm due to a lack of knowledge of ME or my needs and that there is a fine line between me being able to function and not being able to leave the bed or not being able to move in bed other than turn a wrist to communicate via stylus and iPad or to turn my legs with effort.

Those interacting with me need to understand my need to conserve energy where possible so I can use the energy I do have to 'do the essentials' in my home and community, such as accessing medical/healthcare appointments and to engage in activities which enrich my life.

Environment: Quiet, not bright, adequate temperature – getting cold/overheating are stressors which require energy. When less well sudden noises like a knife being used to cut something create a physical response which translates as pain, as does the washing machine, dishwasher, vacuum cleaner, so these items have to be used when at a higher baseline.

Planning: It is essential to have a 'baseline,' a core routine. Whilst there are days I am more able than others, by knowing what is required of me I can plan to use my energy wisely and not exceed my energy limits. Planning enables me to have access to food/fluids/basics when at lower levels of function.

Reaction: Minimising the need to 'react' is essential. I need to minimise the need to react as far as I am able to.

Reaction causes a physiological response which affects the already out of balance central and autonomic nervous systems.

Reaction is required when unplanned events take place.

As my baseline lowers rection results from sound, movement, light causing a startle reflex which translates into pain.

Being forced to react results in an exacerbation of symptoms and causes harm (***see PENE above***).

Information Processing: I can understand & process ideas when within my baseline.

I am a very capable and organised individual. I do not need suggestions or to be prompted how to manage or organise my home or actions. I do need support and routine in able for me to retain the systems created in my home to manage whatever my current level of function is.

- When more unwell I struggle to understand what is said to me, cognitive deficits in ME are exacerbated as energy decreases.
- Listening, understanding/processing & formulating a response is difficult for me when energy is limited.
- Limiting multiple inputs, not using energy is vital to enable me to improve from a period of deterioration (PENE).
- It is important that you allow my brain to process things at the speed it is capable of, if you interrupt my thinking you require my brain to listen and process what you are saying which stops me being able to focus on my thoughts. Effectively you force me to multi-task, which I cannot do.
- The same applies to finishing my sentences, please do not. I will pause on occasion whilst I find words, but interruptions or 'helpful additions' require me to respond to you rather than to complete the thinking process I am in.
- It is easy to regard me as high functioning when engaging with me through documentation or when I am engaging with you based on information I have previously processed and internalised.
- Expecting me to receive information, hear, process, consider and respond 'on the hoof' is hard cognitively, for instance I cannot transfer a phrase from one screen to another on the laptop as short-term memory is defunct, I need to have the iPad screen adjacent to the laptop to copy information. I have adapted to find ways to manage.
- Receiving unplanned telephone calls and being given information results in me not having that information in my head immediately after the call.
- Please ensure any telephone call is pre-planned by email at a convenient time for both parties, with the option to change depending on my current baseline.
- Please provide an agenda or items to be discussed in advance of any engagement so I have time to think in advance and make notes to ensure am able to communicate effectively.
- Giving directions is difficult, it is hugely energy draining. That part of the brain is known to be one of the first lost in ME. It is important that any directions I give are listened to carefully, without interruption, movement or sound as these interrupt my thinking and can, when less able trigger the 'overload phenomena' in ME.
- There are days when giving directions is beyond me, speech is incredibly difficult and the requirement to speak can push me into total non-function when I need silence, no input and absolute rest
- **It is through careful planning and management** that I may appear as though 'I can manage.'

- The essential activities required to live alone account for only a small percentage of my week.
- Activity is only possible by balancing it with adequate 'shut down' periods where I minimise the use of energy, recovery periods account for the rest of my week.

As I deteriorate:

- I experience loss of orientation which increases the risk of falls, banging against things, dropping things.
- I feel very unwell, muscles tire and weaken, ME symptoms increase, cardiac pain increases
- I experience a huge energy drain and need peace, dark, quiet, no interaction, hydration and absolute rest.

At the most extreme: Please see my Medical/Emergency File in my bag hanging on my mobility scooter

- I will enter a phase of paralysis caused by a neurocognitive shut down as the body enters a hypometabolic state which is protective. The minimal energy available is directed to core organs, the brain stops all non-essential activity, speech goes, no movement is possible other than with immense will power I can get a message from my brain to my finger to make it move very slightly to create slight pressure to indicate a 'yes' to a question asked of me quietly, close to my ear whilst holding my finger to receive my finger pressure response. Please be aware the response is delayed as the message from my brain to my finger takes time.
- Heart rate slows to the 30s, BP drops to 100+/60+ from its usual 140-160/90-120 or higher, core body temperature can rise but arms and legs, the extremities are freezing and cold to the touch, or core temperature drops to 33.4 – 35, basal temperature 35.5°

My best hope of recovery is not to be exposed to:

- Ambulance staff as my presentation and needs do not fit with their training
- Being moved or a journey
- An ED triage experience
- An ED stay
- Admission to a ward – I need to be in a quiet room on my own

All the above will delay my recovery to a baseline where I can move in bed, take food & fluids myself.

My presentation and needs are not supported by Home Care, Ambulance, ED/Acute care protocols.
The imperative is not to trigger the most extreme events in order to mitigate against harm

The most effective plan available is to acknowledge my needs and to understand the implication and risk of harm to me when these are not met by understanding the 'why' of them and working in partnership with me to mitigate against risk by pre-planning is

When my energy is exceeded & symptoms increase I need to be facilitated to rest, as the energy drain is not 'mended' by sleep, returning to higher function may take hours, days, weeks or may not happen, depending on the severity of the trigger and my baseline when that trigger occurs.

The HSE's Accessibility Guidelines and the National Healthcare Charter commit to acknowledging & meeting my needs by meeting medical, healthcare & home support staff who are knowledgeable about the pathophysiology of ME (relevant to their role) & who work in partnership with me.