



CHRONIC ILLNESS
INCLUSION PROJECT



Turning the Remote Access Revolution into Reasonable Adjustments

Guidance on including disabled people in face-to-face meetings using videoconferencing technology

“Now that colleagues have become familiar with remote technology, I feel more confident to express my needs in terms of reasonable adjustment.”

“Watching everything reopen offline ... will the new-found accessibility of online work and social events, meetings, conferences, everything ... just slip away again?”

“Remember that people you deny access to are already so isolated because of society and their disability. Please don't further it by excluding us from events!”

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Summary

Remote access using videoconferencing software is a crucial tool for equality and inclusion for many disabled people who are not able to attend face-to-face meetings and events.

This 'best practice' guidance is based on a survey of disabled people's experiences of remote access before March 2020. It is not about how to do remote access when all participants are online, as happened during 'lockdown' in response to the Covid-19 pandemic. It is about including disabled people within society who will remain confined to their home after lockdown ends. Many of them have energy limiting chronic illness (ELCI).

Videoconferencing has rapidly become a mainstream communication tool in many areas of life. Remote access is now an issue of disability justice and equality for disabled people who are housebound. Experiences of disabled people requesting and using this facility to date have been very mixed.

We consulted with followers of the Chronic Illness Inclusion Project about the barriers they had experienced to requesting and using remote access, as well as their recommendations and advice for improving the experience.

The barriers they reported were technological, but also attitudinal and organisational. Some cases clearly involved disability discrimination.

The solutions involve investment in the right technology and capability, as well as learning the relational skills needed to facilitate remote access. What's also needed is also a culture change in understanding why some disabled people require remote access, and this involves confronting ableist attitudes towards energy limiting conditions.

Facilitating remote access has the potential to significantly improve inclusion and participation of disabled people in work, education, civic and political engagement, and social activities. We hope this guidance kickstarts the culture change needed to open up these horizons for our community.

1. Introduction

Covid19 brought about a seismic shift in how we connected and communicated with each other through digital channels. This has undoubtedly created, or worsened, the problem of digital exclusion for some groups of disabled people. For others, however, especially those of us already housebound due to ELCI before pandemic, the remote access revolution unleashed by the lockdown brought us a new form of inclusion. We found our horizons broadened and our participation enabled as never before.

When speaking about their experiences of remote access through Covid19 our respondents said:

“It has been a positive experience to participate in meetings I would have normally missed out on completely.”

“Remote access linked me to opportunities and community.”

“Remote access has made me feel more included and that a part of the 'outside' world is coming to me.”

“Remote access has been life changing as it gave me the opportunity to mix with other people.”

Many of us hope this new experience of access and inclusion will remain in place after lockdown arrangements end.

This guide explains the legal duty to extend the provision of remote access after lockdown, as well as technical and organisational best practice for ensuring meaningful inclusion and participation.

1.1 What are remote access and videoconferencing?

Remote access enables users to connect to and participate in meetings when they are physically far away.

Videoconferencing is a system with video cameras connected by the Internet or by a special connection so that people in different

places can see and communicate with each other, so they do not have to travel to meetings.

Meetings where some people attend in-person and others attend online from a remote location are sometimes called 'hybrid' meetings.

1.2 Who needs remote access?

Remote access may be required by disabled people who cannot attend in-person meetings at all, or without causing 'flare up', 'crash', or deterioration in their health as a consequence, even if other accommodations or adjustments are provided (see Glossary in Section 4.5 for further explanation).

Remote access is not, and should never be, an alternative to accessible venues, personal assistance, or mobility support or other Independent Living support that enable disabled people to travel and participate in face-to-face meetings.

Disabled people who require remote access may be those living with ELCI, or energy impairment, or who are neurodivergent or living with mental distress.

'Energy limiting chronic illness' and 'energy impairment' are new terms developed through a research project by, and with, disabled people living with chronic illness. Our report, *Energy Impairment and Disability Inclusion*¹ describes our process and findings. See Section 4 for an explanation of ELCI and why people with energy impairment may not be able to participate in in-person meetings, even with traditional access arrangements.

Some of us identify as 'housebound'. This is a controversial term among disabled people which we explore further in Section 4.4.

¹ See <https://www.centreforwelfarereform.org/uploads/attachment/681/energy-impairment-and-disability-inclusion.pdf>

1.3 Remote access and the Equality Act 2010

Sections 20 and 21 of the Equality Act require certain organisations to make reasonable adjustments to mitigate substantial disadvantage experienced by disabled people in comparison with non-disabled people. A reasonable adjustment may include an “auxiliary aid” such as a videoconferencing facility to enable a disabled person to participate in an event which they would otherwise be excluded from.

The duty to make reasonable adjustments applies to government departments, employers, education providers, and membership associations, (including political parties), among others. Failure to make reasonable adjustments constitutes unlawful discrimination. Furthermore, the duty to make reasonable adjustments for disabled people is anticipatory. It is not about waiting for a disabled person to ask for changes to be made.

1.4 What kind of meeting or event?

This guide covers meeting or events within these contexts:

Employment: including team meetings, training and workshops

Higher Education: including lectures and conferences

Political meetings: for members and officers.

Civic participation and co-production activities

Telehealth care (where healthcare appointments are conducted remotely) is another important area of development that lies outside the scope of this study. We strongly recommend research into the experiences of telehealth care of people with ELCI.

1.5 Note on the limitations of remote access as an inclusion tool

Remote access can never fully substitute the experience of face-to-face interaction and participation. It is a crucial tool for disabled people whose impairments cannot be sufficiently mitigated by other adjustments and accommodations to permit in-person participation. However, it should not be used as a

universal inclusion tool. While remote access offers increased opportunities for many disabled people, it also creates barriers for other disabled people.

Remote access should never be used as a cheaper alternative or shortcut to the support many disabled people need to get out and participate in work, education, civil society or community life.

1.6 About our research

This case study is based on an online survey conducted between 10th and 23rd June 2020. The survey was open to anyone and was disseminated amongst the followers of the Chronic Illness Inclusion Project asking them about their experiences of remote access (or asking for it) pre-lockdown. We received 93 responses. However, we excluded 6 responses as their experiences were not in scope (i.e. of remote access during lockdown when it was the only option for access and participation for all).

Nine out of ten respondents defined themselves living with ELCI. Almost one in five reported living with mental distress or a mental health condition. Among the “Other” reasons for requesting remote access were chronic pain, multiple chemical sensitivity and autism.

63% of respondents described themselves as completely housebound or often/sometimes housebound.

2. Barriers to remote access

Our survey identified three main types of barrier to remote access and participation: attitudinal barriers, technological barriers and organisational barriers.

2.1 Attitudinal barriers

"I now know it was never true that these accommodations were impossible for you to make, you just didn't want to and in the process of doing that, you've shut me out of public life. It's been an absolute heart-breaking and isolating experience to be shunned from the world in that way."

Our research identified that people with ELCI frequently encounter invalidation and disbelief of their impairment experience. Energy impairment is frequently dismissed as a universal experience of "feeling tired" that is not deserving of the concessions and accommodations provided for disabled people. As a result, people with ELCI are often unsure of their legal status and rights as disabled people.

Invalidation and disbelief of energy impairment create barriers in terms of:

- a) disclosing disability and asking for reasonable adjustments, and
- b) accessing reasonable adjustments because organisers don't associate energy impairment with disability equality legislation

Refusal and discrimination

72% of respondents who requested remote access were denied this adjustment. The reasons given were:

1. Technological reasons. Many respondents stated that were told that could not access the event due to, for example, poor Internet connection at the venue,
2. Vague bureaucratic reasons were often cited. Respondents simply stated that they had been refused because of 'the

rules', while another participant stated they were told 'there is nothing in the rule book'.

3. Restrictive attitudes from organisers. For example, one respondent highlighted that the organiser had told them '*it's too disruptive to have mixed methods*' [remote and face to face]. Another respondent had simply been told asking for remote access due to disability was '*not a good enough reason*'.
4. Although not normally stated as a reason for refusal, several respondents sensed that organisers thought they were simply unwilling to make the effort to attend in person. One respondent said:

'Sometimes I had to attend in-person [at detriment to their health] just to show willing'

Some of these examples clearly involved disability discrimination, in breach of the Equality Act 2010.

An afterthought

When remote access was provided it was often done half-heartedly, with no support provided to facilitate connection and inclusion of the remote attendee:

"I was dependent on someone remembering to 'dial me in' and they forgot."

"At a conference I could not speak as my connection was not monitored outside of my speaking slot."

Two tier status

Trying to provide remote access without any prior planning or resources puts a strain on those leading the meeting, and makes remote attendees feel like a burden:

"I was mostly dependent on the goodwill of others to include me in the meeting."

“The setup and arrangement make me feel like a burden. It also emphasises emotionally that I’m stuck here at home and everybody else is together, so it really hurts.”

The result is that the remote attendee has second class status within the meeting or event:

“I felt like an outsider and less listened to. A point made remotely has less impact than the same point made in person present physically at the meeting.”

“I feel excluded because I can’t be part of the small talk on the side.”

2.2 Technological barriers

“When you’re virtually attending an “In Real Life” meeting you have people who are closer to you being louder and people further away being softer, you have trouble seeing because the camera never includes everybody who talks, and people talk on top of each other.”

Nearly all respondents reported problems with hearing and seeing the proceedings of a meeting, and sometimes with being seen by other attendees in the room. This was due to lack of adequate equipment and poor internet connection as well as equipment being badly installed and utilised. The following technological problems with sound and video invariably create barriers to participation and inclusion:

- Poor internet connection. This limits the framerate, making visual information, as well as sound, difficult to process because the screen “freezes”.
- Inadequate equipment for sound and vision, especially lack of adequate microphone
- Poor positioning of devices
- Equipment and installation not tested beforehand
- Any visual information being presented may not be fully accessible, perhaps due to low resolution or limitations of camera placement

“No-one placed the screen where I could see or be seen. I had to shout to ask to take part and couldn't follow half of it”

Lack of technical support for remote attendees

Another major barrier for respondents was not having adequate equipment or internet connection at their home in order to access the videoconferencing platform, or not having support to install and navigate the software.

2.3 Organisational barriers

“It can be hard to break into a conversation or to ask a question, unless the moderator or chair is skilled at including everyone.”

The barriers arising from the organisation of meetings and events reported by our respondents included:

- Attendees talking all at once makes it harder to speak up
- The Chairperson not actively including and involving remote attendees
- Not being able to join in with networking during breaks and at the end of the meeting
- Feeling like a minority makes it harder to be heard or get my points across
- The larger the meeting, the more difficult is it to hear well or see what is going on.

“The more people in the meeting the more cognitively challenging it is.”

2.4 Issues with ELCI and cognitive fatigue

Most respondents with ELCI mentioned that, although they wanted the opportunity of remote access, the technological aspects of hearing and seeing via an Internet connection created a bigger cognitive challenge than the face-to-face alternative.

“The biggest problem is that the cognitive load (and therefore energy usage) is ENORMOUS.”

Problems with sound and video exacerbate sensory intolerance and cognitive fatigue:

"I have severe sensory intolerance so background noise, delays, feedback loops, or glitches can and have affected me."

"If the sound isn't clear that makes it very hard to concentrate."

It takes longer to process information as well as to respond. This goes for written contribution as well as verbal:

"Verbally I need more time to process before speaking."

"There's also the option to type but I am slower than most people. I also cannot write / type and listen at the same time."

Several respondents stated that they could only participate in short bursts with rest breaks in between. The length of any meeting or event was a main determinant of successful remote participation:

"Fatigue meant I could not keep up and needed to rest due to sensory overload roughly every 15 minutes."

"The workshop lasted several hours without breaks and any meaningful participation required being online the whole time which isn't possible for me."

This may mean that a remote attendee may manage to listen to proceedings but not actively participate due to cognitive fatigue:

"The cognitive load of just listening is overwhelming already. Some meetings I didn't have the energy or cognitive ability to participate actively."

3. Solutions for remote inclusion and participation

Key Recommendations

- **The technical side of remote access is crucial to ensuring inclusion and participation, but the attitude and commitment of organisers is just as important**
- **The role of the remote access facilitator is essential**

3.1 Changing cultural attitudes to remote access

“Understand that if someone needs to use remote access then they have a good reason, so act like they are in the room.”

“Remember we are people, not just an image on the screen.”

It's important that remote access is understood as a disability equality tool. As such, it must be prioritised and planned ahead of an event, and not provided as an afterthought.

- Accept that if someone requests to participate remotely in your event it is probably because existing access provisions do not enable them to participate in person. It's OK to ask if there are any further accommodations you could make that would enable them to participate in person. It is not OK to question their impairment, their request, or their commitment to.
- For on-going events involving hybrid attendance, invest in quality equipment such as computer, microphone for organiser, headset microphone for attendee, and in broadband capability. Consult an IT technician where possible.
- For larger events such as conferences, recruit and train facilitators in advance in both the technical skills and the organisational skills required for remote access.
- Ensure that the Chairperson and facilitators understand why remote access facilitates inclusion and participation for

people with energy limiting conditions, as well as other impairment groups.

- Always trial your equipment and installation beforehand to check everything is working and organisers, as well as attendees, are familiar with procedures ahead of the event.

Meeting online by default?

“It’s almost impossible to avoid a two-tier sense of status and inclusion with hybrid meetings” (Inclusion Scotland). Remote attendees are unlikely to be able to fully interact with and influence other attendees on an equal basis with those in the room. The best way to level the playing field for remote attendees is to make your meeting or event online by default. For example, work team meetings could be conducted online so that employees in an office participate alongside those working from home in the same virtual space.

3.2 Technical solutions

Key Recommendations

- **Best results will be achieved with the involvement of an IT technician, both for the organiser and the attendee of the meeting.**
- **However, with commitment and creativity by organisers, remote participation can be achieved without professional IT involvement.**
- **Always have a trial of your technical set up before the event to check that it works and everyone knows their role. If possible include the attendees in the trial.**

Hardware - what devices to use?

A **laptop** is usually the best solution, but a tablet or smartphone may work if it has sufficient processor power for long periods of

use. A device with low processor speed and/or memory capacity will become “choppy” in performance. The software platform you use will provide specifications for processor power. The device needs to have a video camera of reasonable basic quality (preferably High-definition quality).

You will need a **microphone** of enough quality and range to pick up all participants in the room that need to be heard by remote participants. You may need to consider having multiple microphone/speaker points to cover a larger room. (E.g. the Jabra Speak 710 Bluetooth speakerphone can be linked in pairs and is a relatively easy, good quality setup).

Software - which videoconferencing platform?

Videoconferencing software is also known as the “platform” for remote access. The platform handles the call and may allow additional functions, such as, mute, text chat, adding additional participants, and screen sharing. There are many options which offer different advantages and disadvantages.

Our respondents recommended Zoom, followed by Microsoft Teams as the most effective and accessible platforms for remote access. Useful features of Zoom include a chat function, screen sharing, captioning and muting, breakout rooms and recording capabilities.²

For smaller meetings with just one remote attendee, Facetime or Skype on a smartphone can work if well facilitated with good internet connection.

Security consideration: Make sure safety and security settings provided by the videoconferencing platform are in use. Do not enable people not known by organisers to share their screen with other attendees

² For an activist's guide to using Zoom by Disability Labour see <https://drive.google.com/file/d/1iKtTA22OpSraXlh3nl76NTfyMvsmmkqM/view>

Internet connection

The internet connection used needs to be as stable and reliable as possible. Broadband speed should be between 400Kbps-1.5Mbps (kilobits per second) for high quality video.

Positioning of devices

“Make a space at the table for those contributing remotely so we have a chance to see people's faces when they talk.”

For a roundtable meeting, position the device as if the remote attendee had a seat at the table, so that they can see as many participants as possible and be seen by all. Position the microphone in the middle of the table.

For smaller meetings it is possible to use a smartphone that is held by an attendee and passed around depending on who is speaking.

Position the equipment so the person dialling in remotely is not seeing people's backs

“Having someone who moves the device as a person would if they were present in the room would help. So, when there's a speaker, ensuring the device is turned to whoever in the room is speaking.”

Technical support for attendees

Remote attendees may require support or resources for:

- Equipment, for example, headset microphones, a suitably powerful device, an additional camera if needed
- Accessing adequate broadband speed
- Support with installing and learning to navigate the videoconferencing platform
- A test call in advance of the meeting to ensure function of sound and video on their device and familiarise with the software.

Quality of Sound

Reduce as many sources of background noise as possible, for example, open windows, loud ventilation systems, doors opening and closing. It can help if you can place the microphone(s) slightly away from where people are sitting or noise sources, ideally elevated slightly. A useful tip is to place the microphone on a padded surface such as foam pad to reduce noise and vibration through the table.

For a roundtable event, place the microphone in the centre of the table so people are equal distances away.

Quality of vision

The visual quality will depend upon stability, reliability and speed of internet connection and processing power of devices.

Additional considerations include:

Visual displays within a meeting/event. If the presenter if people are drawing on a whiteboard, the screen resolution isn't normally good enough to see very well. The presenter sharing their screen with remote participants is the best solution.

Being seen by other attendees. In a large meeting the remote attendees will not be seen adequately by the other attendees. Consider using a projector to display the remote attendees' screens.

Enable choice over video presence. Some remote attendees may prefer not to turn on their video and this choice should be respected.

3.3 Organisation of the meeting/event

Key recommendations

- **Chairing skills and considerations are the same as for face-to-face meetings, but are even more important when including remote attendees**

- **The facilitator and the Chairperson must be separate roles, but they should work closely together**

Chairing a hybrid meeting well involves

- Agreeing in advance how remote attendees will signal when they want to speak. This could be through electronic “hand raise” or visually raising their hand.
- Inviting remote attendees to introduce themselves at the beginning so that sound or visual issues can be picked up before the meeting/event gets going.
- Making it very clear to all attendees that the person(s) joining remotely is a full part of the meeting.
- Ensuring remote attendees know how to communicate about any technical problems.
- Creating space for remote attendees to speak by inviting them rather than waiting for them to contribute. Always ensure they can ask questions on an equal basis.
- Ensuring contributors speak one at a time is especially important for those attending remotely to follow events.
- Controlling the pace of meeting so remote attendees have time to process information and speak up.
- If possible, creating opportunities for informal chat between remote attendees and those in the room during break times or at the end of a meeting.
- Muting remote attendees microphone if there is more than one remote participant.

The facilitator role

All hybrid meetings involving more than three or four people need a remote access facilitator, separate from the person chairing the meeting. The role of facilitator is to ensure that remote attendees are as fully included as possible. For smaller roundtable meetings, a fellow attendee may be assigned the facilitator role without detracting much from their own participation. They should, however, be recruited and prepared for the role in advance. For larger and more complex events, such as conferences and workshops, the facilitator would need to be a specialised role,

recruited and trained well in advance. Some organisations have found that at least 2 facilitators are needed for larger meetings. In these cases the facilitator is akin to a Communications Support Worker.

The facilitator should have the technical knowledge to help the remote attendee/s with issues such as sound and installation of software beforehand.

Tips for facilitating remote access include:

- If using Zoom or MS Teams, use the chat function within the software to communicate with remote attendees without disturbing the meeting.
- Provide another channel of communication (eg SMS messaging or Whatsapp) for attendees to make contact in case of technical problems with software or equipment during the meeting.
- Check in to ensure that sound and video are working at regular intervals.
- Remind those in the room at regular intervals of the presence of remote attendees so they feel included.
- If technical issues prevent the remote attendee from speaking, convey their contribution on their behalf.
- If using a tablet or smartphone, move the device around the room so the remote attendee can see and hear the speaker as well as possible, or change the viewing angle of a laptop.
- Facilitate networking and informal conversation by finding out if the remote attendee wishes to speak to someone in particular outside of formal proceedings.
- Find out in advance which part of the meeting/event matters most to remote attendees and make sure they get their say at this point.
- Provide feedback on the remote attendees' experience for future meetings.

3.4 Adjusting meetings for energy impairment and cognitive fatigue

Remote participation in meetings is often more cognitively challenging than in-person participation. Our respondents gave the following advice for making remote attendance as accessible as possible for people with cognitive fatigue.

- For long events, consider breaking them down into shorter sessions over several days, rather than full days.
- Build in rest breaks if the meeting lasts more than one hour.
- Enable the remote attendee to pace themselves and build in their own rest breaks by providing a detailed agenda with timings beforehand.
- Understand the remote attendee may need to miss sections of an event or leave a meeting early due to cognitive fatigue.
- Provide as much information as possible about the meeting before and after. This enables remote attendees to process information at their own pace rather than within the meeting.
- Ensure speakers speak slowly and don't move around while speaking.
- Record the meeting (most videoconferencing platforms have this facility) so that attendees can watch parts that they missed after the event.
- Use live captioning to create a transcript of the meeting to send to attendees after the event.
- If a remote attendee is presenting at the meeting, allowing them to record their presentation in advance enables them to save their cognitive energy for answering questions.
- Lastly, be aware that even with all these access provisions in place, some people with severe energy impairment will still not be able to participate in your meeting or event and may require alternative ways of contributing, e.g. by email.

4. About ELCI and energy impairment

4.1 What is ELCI?

Energy Limiting Chronic Illness (ELCI) is a long-term condition characterised by a debilitating mix of physical fatigue, cognitive fatigue, and pain, alongside other diverse or fluctuating symptoms. The overall impact of our condition is significantly reduced energy for essential everyday activity. Living with ELCI means having to carefully ration limited energy in order to accomplish basic tasks and avoid aggravating symptoms.

4.2 What is energy impairment?

Energy impairment is a term we have developed to convey the experience of energy limitation as a type of impairment or disability. Energy impairment is the main feature of ELCI but it may also be experienced by people with other impairments or health conditions as a secondary feature. Energy impairment is a form of hidden impairment.

4.3 Why are face-to-face activities difficult with ELCI?

For people with ELCI, energy impairment is a global impairment. That means it affects nearly everything about how our bodies and brains work. ELCI affects mobility (walking), cognition (eg thinking, reading, communicating), in fact nearly every kind of activity, as well as our body's response to sight, sound and smell and temperature. A sub-group of us also have multiple chemical sensitivities.

It is more difficult to accommodate the global impairment with ELCI than to accommodate a single impairment. Adjustments and support may help with one aspect of our impairment, but not enough to mitigate the overall impact.

Going out to a meeting or event requires many units of energy. Getting ready to leave the house, travelling to the venue, interacting with other attendees, listening to and processing what's being said, speaking up, sitting upright, sustaining concentration, coping with background noise and artificial

lighting, then travelling home again – all of these individual tasks or challenges are a drain on our very limited reserves of energy. When we do them all in a sequence they can result in a “**crash**”, or in days or weeks of “**payback**” (see Glossary).

For people with moderate or mild energy impairment, adjustments such as travelling by taxi, having supportive seating, or being able to lie down for a rest could make a meeting or event accessible. But for others, no amount of adjustments or support can make an in-person event accessible. This also holds if we have already used up our daily or weekly energy budget on other activities like household management or a social activity.

Therefore many of us use the term “housebound”, and why we wanted to create a research practice that our participants could take part in from home or bed. [See appendix/link to website for more explanation of why we identify as housebound]

Some people with ELCI say they are completely housebound. Others say they are not completely housebound but taking part reliably in activities outside their home is difficult because of fluctuation and **payback**, which are two key features of ELCI.

4.4 Housebound vs Trapped at Home

We believe there is a crucial difference between being housebound (or bedbound) due to severe energy impairment, and being trapped at home, or in bed, due to a failure of independent living support or access provisions.

Some disabled people reject the term “housebound”, for very important and valid reasons. Disabled people have been labelled as housebound when they could in fact access the community if external barriers were removed, and appropriate accessibility measures and assistance were put in place. The term housebound has been used to justify the exclusion and institutionalisation of disabled people against their will.

However, many people with severe ELCI claim the term “housebound”; (and/or “bedbound”) to capture a crucial and

defining aspect of our identity and experience that cannot be addressed by removing social barriers, or having personal assistance.

Energy impairment is a global form of impairment. It affects physical, cognitive as well as sensory function. This means that for people with severe ELCI, no amount of personal assistance, technological support or other adjustments are enough to mitigate the impact of their impairment and enable them to leave their home and participate in society.

Identifying ourselves as “housebound” does not mean we don’t need or want assistance and adjustments to have lives of equal value as participate as much as possible. It means the support and adjustments we need in are different. They often involve access and participation from home or bed.

Making the distinction between disabled people who are housebound and those who are trapped at home allows us to place the needs of both groups on an equal footing and fight for equality and inclusion together.

Some people with ELCI say they are completely housebound. Others say they are not completely housebound but taking part reliably in activities outside their home is difficult because of **fluctuation** and **payback**, which are two key features of ELCI.

Because there is no better word to describe these experiences, we use the term housebound to include people who are not completely housebound, but have difficulty participating in activities outside their home because of ELCI.

4.5 Glossary of ELCI terms

Crash

Noun - A state of body-mind shutdown, resulting from over-exertion and/or exposure to stressors (e.g. environmental,

emotional, deregulation of eating or sleeping, unexpected event).

Verb – to become incapacitated through dramatic energy deficit. Experienced as pulling the plug out, blowing a fuse, hitting a wall, or a computer crashing from having too many apps open or running out of battery power.

A crash is when we can no longer push through symptoms. A crash can happen during activity or event once our energy budget is spent, as a result of not pacing, conserving or recharging energy as needed. A crash can happen the next day or days following over exertion or can be immediate.

Payback

The increase in symptoms and/or loss of function that results from spending energy outside of our energy budget.

Some of us are able to “borrow” energy from tomorrow to use today, but we have to “pay it back” afterwards. We may choose to incur payback for an activity or event that is valuable to us. Or we may judge that an activity or event is not worth the payback that follows.

Written by Catherine Hale and Alison Allam, with input from Phyl Meyer and Fran Springfield.

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Citizen Network
FOR A WORLD WHERE EVERYONE MATTERS

For more information about the CIIP please visit:

www.inclusionproject.org.uk

Twitter: @chronicinclude

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