

Private & Confidential

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Luna Marotta (20/11/2003) Support Plan

Background Information

This support plan is intended as a guide to help understand and support Luna's physical symptoms. This is for use by the core group of professionals supporting Luna in Social Work, Education and Health. It may also be useful for this to be shared with others involved in supporting Luna, with her consent. It is essential that everyone supporting Luna is aware of her support needs.

Luna has a diagnosis of Autism Spectrum Disorder (ASD) and has intellectual abilities (thinking skills) in the Very Low range. This means that:

- It may be difficult for Luna to always **understand what people mean** from what they say and do (e.g. to pick up on someone's tone of voice or body language);
- She may struggle to understand what **other people are thinking** or why there are behaving in a certain way, especially if it is different to what she is thinking or doing. This might mean that other **people's actions are confusing** for her;
- She finds it **difficult to cope with change** and can become distressed in response to last minute changes of routine.
- It may be difficult for Luna to **understand lots of information at once** (e.g. complex ideas about her symptoms or why something is happening);
- It might be difficult for her to **keep information in mind** (e.g. act on instructions) or recall it at a later time (e.g. to remember an appointment or recall what to do);
- She might find it difficult to **know** how she is feeling making it difficult to know what emotion to show to others (e.g. laughing when upset);
- If Luna can't always tell **how she is feeling inside** (e.g. her emotional state) it will be difficult for her to describe this to others or know how to ask for help. This means she **may not ask for help** in a typical way e.g. by using words;
- If Luna doesn't understand her own emotions or isn't able to express them in words then she may also struggle to know how to manage (regulate) them. This means that she needs the **adults around her to prompt** this for her;

- Luna has areas of special interests which she really enjoys and which can be used to **help develop her skills**;
- Because Luna has some areas of strengths it may mean that people assume she is more able than she is. People **may overestimate her ability** to understand information, express emotions or self-regulate;
- Luna experiences pseudo-hallucinations which can also **cause distress**;
- When Luna is distressed it will be much more difficult for her to communicate her needs, to use her thinking skills, to know how to cope and manage her emotions (self-regulate). She may use **self-harm as a way of coping** with difficult feelings.

Since March 2019 Luna has experienced a number of persistent physical symptoms including seizure-like events where Luna will often drop to the floor and begin shaking and twisting her limbs and reduced mobility (e.g. leg weakness.) These symptoms have been fully investigated and are known as **functional symptoms**. This means that there is no underlying disease causing these symptoms, but her nervous system is sending the wrong messages to her brain, much like a software problem on a computer.

For many young people these symptoms are triggered by distress. People who experience adversity, who struggle to understand, communicate and cope with their emotions, like Luna, are particularly vulnerable to these functional symptoms. The symptoms are the body's way of communicating negative emotions. Unfortunately, the symptoms themselves and the response of people around her can cause further distress and maintain the symptom cycle.

Treatment of functional symptoms should involve several approaches:

- Identifying and treating the underlying cause of distress; ongoing distress means that Luna's resilience is constantly being pressured and makes it difficult to find a better way to cope.
- Supporting Luna to understand and communicate her emotions so that she can express emotions in a safer way.
- For the adults around Luna to respond to the symptoms in a consistent and containing way. It is important to remove any secondary gain so that there is no benefit to Luna from these symptoms (such as avoidance of stressors or the presence of a parent).
- If the functional symptoms are a way to elicit a desired response from the adults around her, then the adults around her should be supported to find a more appropriate way to meet these needs. It is important that these needs are met at all times and not only when the symptoms occur.
- Professionals and adults working with Luna should understand these symptoms as a **communication of distress**. It can be unhelpful to try to 'catch out' a young person with these symptoms as it can build distrust and ultimately cause more distress, adding to the symptom cycle.

General approaches to help prevent functional symptoms

These approaches are aimed at reducing generalised distress for Luna by making the world safer, more containing, more predictable and easier to cope with:

- Luna needs consistency; this means all of the adults supporting Luna in a similar way.
- Luna will work best in a structured routine at home and in school. This means developing a routine, showing and describing that routine for Luna using a visual plan, and sticking to it.

- Luna will require reminders/repetition of the routine. This is because she may a) struggle to retain/recall it and b) may test the boundaries/consistency of the routine.
- Luna may need help planning and sequencing. The routine/visual timetable can help this by encouraging her to identify what she is doing now and next; so that she gains a sense of control and predictability.
- Luna needs extra support in managing transitions and changes to the routine. She benefits from visual information and from advance notice of changes (not too soon and not too late). She benefits from 1 week to prepare for change then 1 week to consolidate the change. All changes should happen in a gradual way.
- Luna will benefit from any long or complex verbal information being backed up by visual information to support her understanding e.g. timetables and handouts.
- She needs extra time to process information or to complete long or complex tasks.
- Luna works well on a 1:1 basis and needs extra support in managing groups.
- It can be helpful to have breaks between demands in a quiet place where she can complete calming activities.
- Luna needs the adults around her to remain calm when she is distressed and to direct her to her coping strategies.
- The adults around Luna also need to model their own coping skills. This includes things like keeping voices low, using clear and concrete language to explain what is happening.
- It is important to continue to support Luna's attendance at school and other activities like Lothian Autistic Society and Nordoff Robbins.
- Luna needs to feel safe around the adults that care for her. She also needs a private space where she has a sense of safety and can be encouraged to use her self-soothing skills. A lack of predictability including changes to routine, new people, unrealistic expectations, unpredictable emotional responses and inconsistent parenting is likely to make Luna feel unsafe and cause distress.
- If symptoms are a means to elicit behaviours from those around her (that meet some kind of unmet need), then those needs need to be met another way. If these needs are met consistently this may reduce distress and prevent functional symptoms from occurring.
- Luna's functional symptoms are unlikely to reduce unless the support recommendations are applied consistently.

- It should be noted that when a consistent plan is implemented there may be an initial period where symptoms are worse before they improve. This is common with any behaviour support plan and may reflect some initial distress related to the change in approach, or may reflect the young person testing the boundaries/resilience of the plan. It is therefore important to stick to the plan if at all possible.
- Try to notice when functional symptoms are occurring as early as possible to prevent escalation. These commonly occur at high levels of distress.
- If you can tell that Luna is becoming distressed, encourage her to use her emotion regulation strategies / sensory strategies (developed with Mihika) in order to prevent escalation. However, be careful to avoid reinforcement of symptoms by only giving her access to or reminders around strategies when symptoms occur. She should be prompted to use a strategies before the onset of symptoms and as part of the ongoing support with her emotional regulation.

- It will be important for school and parents to offer praise for things not related to her symptoms e.g. getting into school, doing homework, staying on task for 15 minutes etc.
- Do not encourage Luna to monitor the frequency of seizures; this should be recorded by school or parents.

Recommendations: when symptoms arise

- Please be reminded that Luna's symptoms represent REAL distress and are highly impairing for her. Do not try to 'catch her out' or question whether the symptoms are genuine.
- Luna does not need any medication. Offering unnecessary medication may in fact cause harm.
- If there is a trigger for symptoms which involves distressing behaviour of others or an inappropriate demand placed on Luna, it is appropriate for those triggers to be removed from Luna's environment (e.g. bullying, being shouted at, sensory overload).
- If the trigger involves a task which is appropriate for Luna to complete (e.g. a certain class at school), the task should not be avoided completely but be introduced in a gradual way over time. This 'graded-exposure' approach aims to stop the body from learning that the only way to cope with pressure is through the onset of functional symptoms. E.g. adapted task in small ASL group gradually building up difficulty.
- Luna does not need to go to hospital unless she inadvertently harms herself during the episode (e.g. sustains a head injury) or the symptom is new/different. School/parents should follow usual advice around what to do following any new injury or symptom.
- If Luna is able to state that symptoms are about to occur, she should be allowed to remove herself from the environment for symptoms to resolve, then return to the activity.
- If symptoms occur in the corridor, allow her to move to a quiet room until symptoms resolve then return to class.
- When symptoms occur:
 - o Do not expect Luna to initiate a strategy or response; if she is distressed enough to present with physical symptoms she is unlikely to be able to generate ideas around emotion regulation.
 - o State "*Luna, I am going to leave you alone now*"
 - o Do not point out that symptoms have started.
 - o Luna should simply be left alone.
 - o She should not be touched or restrained.
 - o Luna does not need to be carried or given a wheelchair.
 - o Luna does not need a cushion or a pillow.
 - o Do not try to use comforting or baby-ing language.
 - o Work should go on around her, keep voices calm, do not acknowledge that the symptoms are occurring.
 - o She should return to normal activities as soon as possible.
 - o Staff should be aware she may be more fatigued and ensure she can access all appropriate supports as outlined in earlier sections.
 - o If Luna loses mobility she should be allowed to sit comfortably and the above advice followed (also consider graded approach to tasks if these events occur during PE, for example).

What to do after the events

- Keep a log of events and see if any triggers are evident for help planning activities at home and in school.
- Do not try to 'debrief' with Luna afterwards; she may not recall the event and further discussion of symptoms may promote secondary gain.
- Review the graded task and increase task difficulty if appropriate.
- Feedback to core health and social work team of any major changes.
- Do not discuss the symptoms when Luna is being collected from school, college or any other activity. It will be useful to agree a specific time where school and parents can check in around this and any other important information.
- Urgent psychiatry assessment is unlikely to be required (or helpful) unless acute psychiatric symptoms arise e.g. severe self-harm, suicidal ideation, new psychotic symptoms or eating difficulties worsen (severe restriction or purging).
- There is a risk of harm if Luna presents to hospital and undergoes unnecessary re-investigation of her functional symptoms. Missed school also leaves a secondary impact on her quality of life. However, there is also a risk to assuming all symptoms are functional. Therefore if any new symptoms appear or if Luna sustains an injury which would normally require medical attention, normal school procedures should be followed.

As noted, it would be important to share this support plan with the adults supporting Luna with consent. We hope that this provides helpful information in supporting Luna. Should you have any questions in relation to this information please do not hesitate to contact us.

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