**SBAR - Care pathway for people with a profound learning and multiple complex disabilities requiring acute medical services/hospital admission.**

**Situation**

Family carers are asking for clarity regarding the acute emergency care pathway for their relative with profound learning and multiple disabilities (PMLD). There is a high level of anxiety that their, or that of known carers, expertise will not be acknowledged or utilised should the person with PMLD require acute care/admission to hospital. The pathway into acute care requires to be clarified and modified for this complex group of people.

**Background**

The coronavirus pandemic has magnified the issues that family carers have had when their relative with PMLD has an acute medical episode and may require admission to acute hospital care. This group are largely non-verbal and may communicate in a way that others find challenging particularly when stressed. It is essential that they are supported by a relative or paid carer that knows, understands them and who the person with PMLD trusts.

Children, young people and adults with PMLD are at significant risk of becoming seriously ill with COVID 19 and given the nature of their complex disabilities will require acute medical services.

Family carers are expert in the care of their relative and have spent a lifetime ensuring that their child/adult is kept as well as is possible and prevented from admission to hospital. Many family carers have become expert in intensive care interventions and in some cases their homes have become mini intensive care units.

PAMIS have been monitoring the issues raised by families of children, young people and adults with PMLD. The caring role has greatly intensified with many now solely caring over the 24 hour period, seven days a week. The stress and anxiety levels are understandably high and yet family carers are still finding time to support each other and to creatively solve issues as they arise.

Accessing acute services remains a high anxiety. We now have examples of poor pathways of care on admission (appendix 1) and there are a number of questions that families would like to be reassured about or to suggest alternative solutions.

**Assessment**

PAMIS has on behalf of family carers raised a number of concerns and questions about care and treatment during COVID 19 shut down which have been supported by actions from Scottish Government guidance. However there are still areas that require further clarification or a different approach.

The question of accompanying a relative with PMLD into hospital was raised in the early stages of the crisis by PAMIS, on behalf of family carers, and there appears to be resolution that they can support their relative during hospital admissions. However there is still concern about how visiting is interpreted at local levels. Questions regarding accompanying the relative in the ambulance requires clarification. Further questions are highlighted in appendix 2 based on a scenario situation written by a family carer.

A group of expert family carers of children, young people and adults have agreed to form an advisory group for those with PMLD to support debate, discussion and insight into some of the key issues that are currently being faced. Their lived experience, knowledge of need and creativity in seeking solutions is key to developing appropriate care pathways for this group.

Harnessing this knowledge and these skills alongside expert practitioners will not only ensure guidance that works for all is developed but also enables family carers to reduce their anxiety by being involved in solution focussed activity.

**Recommendations**

1. PAMIS to set up an expert family carer panel to advice on an appropriate acute hospital care pathway for children, young people and adults with PMLD
2. Invitations to support the expert carer group should include
   * Isla McGlade – Chief Nurse NHS Grampian/ Scottish LD Nurse leads group
   * Lesley Holdsworth – Clinical Lead for Digital Health and Care , Scottish Government
   * Charlie McMillan SCLD
   * Dr Susan Buck – Lead for CEN
   * Alison Marshall - Learning Disability Liaison Nurse NHS Tayside
   * Paul Madill - Public health consultant NHS Fife
3. Other key stakeholders to be identified following the first meeting
4. PAMIS to develop scenarios for first meeting to shape discussions re care pathway (see appendices)

**Appendix 1 – Recent acute hospital admission experience story**

Miss X is 34 years old and has a profound learning and multiple disabilities. She has been cared for 24/7 at home her entire life with some day carer support. However this additional support ceased once the Covid 19 epidemic hit in order to minimise exposure / foot fall through the house. This has caused a huge strain on the whole family (mum, dad and younger brother) and as they applied the social distancing to the letter this meant only limited additional family support from out with that hub such as provisions of groceries.

Despite taking every precaution possible including shielding Miss X from activities and carers well before the lockdown and adhering strictly to the guidance provided, the family have found themselves in the position where despite initially appearing to thrive with her family’s close care – Miss X has ended up in a Covid Red Zone Ward within an acute hospital. Miss X had a significant infection, suspected pneumonia, and a possible UTI. The 1st & 2nd Covid Test result have both been reported back as “not detected”.

**Hospitalisation**

The family were, as many families caring for a PMLD adult are, concerned about hospitalisation and what support would be allowed under Covid restrictions.

Initially a home assessment was made of Miss X, following call to 111 due to nausea, sleepiness and general lethargy. Her chest was checked and oxygen saturation level appeared to be fine. As she had already started oral antibiotics it was decided to continue that treatment at home and to continue shielding at home and avoid hospitalisation

Support from the Hospital at Home Team was recommended to allow rehydration through drip or possible catheterisation whilst avoiding hospital however that was not available as the Team were only visiting Covid 19 positive patients in the community.

There was no improvement overnight and a general malaise the next day which resulted in a further call. It was requested that Miss X go in for clinical assessment into the red zone, asking initially if she could come in alone. Fortunately following an explanation of her complex needs and lack of communication Mum was allowed to accompany her as the main carer. However the family note that the general acute services are poorly equipped to deal with people with PMLD and their carers at the best of times. Issues they encounter on a regular basis and on this visit included:

* Hoist availability and staff who are competent in using them
* Long delays in hoisting
* Inadequate access to shower facilities for people with PMLD e.g. a shower chair but no harness/support
* Clinical staff unwilling to listen to family carers/acknowledge their expertise
* Lack of dietary support - Miss X required a liquidised and dairy and gluten free diet.
* Lack of dietary support for carer who was only offered toast at 9pm following full day in admission unit (which she ate despite having a gluten intolerance)

Miss X is currently being treated for significant infection – possible pneumonia/ sepsis, / UTI with IV antibiotics and has had to have a catheter fitted. She has been moved from the assessment red zone to a main red zone ward despite “not detected Covid” results x2

In addition the family report a number of other concerns:

* Mum contacted the learning disability team who were unable to visit as Miss X is in a red zone, despite 2 x Covid 19 “not detected” tests. The family are concerned that if Miss X has not had Covid 19 she has gone from a close family shielding unit to a hospital red zone.
* Early discussion around DNR forms and what support would be available going forward. This was when she was really unwell but the family are questioning the accuracy of the assessments as they felt inappropriate equipment was used e.g. blood pressure taken with an extra-large adult cuff, and the oxygen saturation levels of 100%.
* The learning disability team has attempted to liaise with Dietician to sort out suitable meals which resulted in an offering of soya yoghurt plus a banana from the staff fruit bowl. A relative attempted to deliver baby rice in order to bulk out the yoghurt and after a prolonged discussion it was allowed onto the ward – with the guarantee that the next day Miss X would get appropriate food from the canteen – this didn’t happen. The relative arranged with the SCN to deliver some easy prep savoury food pouches so Miss X could have something to eat. The family member came up with the same security issue. Security had been instructed not to allow any bags unless in exceptional / essential circumstances. The family quite legitimately felt that basic food provision is essential.
* The Dietician eventually arrived for discussion around diet and confirmed only fruit pot / soya yoghurt or sausages available and that nothing can be liquidised on site. A soya based meal supplement was offered, but the boxes did not list ingredients and the dietician was unable to provide a data sheet. The family correctly highlight that this is not a complex diet and surely the canteen would have had baked potatoes and vegetables available all of which could have been mashed up.

The family escalated these general basic care concerns to one of the general managers. This resulted in contact from the Catering Manager who highlighted that there should have been a wider variety of dairy / gluten free options discussed. Finally a breakthrough but only after significant additional stress for all concerned.

On the positive the mum was allowed to remain with Miss X however the family feel that this was due to necessity as the staff would not be able to deal with her complex needs or be able to “read her signs” appropriately.

The family shared this story in the hope that it would support discussions about how people with PMLD and their family carers should be supported within the NHS acute settings. They wanted to highlight the huge gap in the acute services understanding on dealing with both profound learning and multiple disabilities (PMLD) , a lack of support for the carers and of respect for their profound (deep, wise and expert) knowledge of their relative to which they are the prime carer.

Appendix 2 -

**Case scenario with accompanying questions to support development of care pathway/algorithm**

Lauren is 31 and has a profound learning and multiple disabilities (PMLD). She lives in supported accommodation with 3 others and is supported in that house by an excellent team of carers from an independent care provider who are funded by Social Work.

Lauren has complex epilepsy which is not completely controlled by anti-convulsant medication and this is currently under review by a neurologist. Her epilepsy manifests itself in partial focal and tonic seizures which are likely to be unrecognised by anyone not familiar with her, including NHS staff, who may perceive them as behaviour. She occasionally has strong tonic seizures which throw her to the ground and she has frequently been injured as a result.

She has very good general health. She is doubly incontinent. She needs assistance with all aspect of her life, including personal care. She is non-verbal and has limited understanding out with her everyday circumstances and routines. It is very difficult for people who do not know Lauren to communicate her. She has little sense of danger. She is physically strong and is very active and mobile. She has been assessed as requiring one to one support at all times.

She will be unresponsive to commands / instructions / guidance that she does not understand, or that she does understand but does not want to cooperate with. She is unlikely to tolerate medical intervention and equipment without someone to support her at all times. She has been assessed by the learning disability liaison nurse as being a high risk in a hospital setting. She has up to date hospital and digital passports.

Despite her learning disability and epilepsy, Lauren is a happy person, with an very good quality of life full of activities, fun, achievements and worthwhile interactions with other people.

**Questions to consider (Attachment 1)**

Given the current Covid 19 situation a number of questions have arisen regarding the care pathway for children, young people and adults like Lauren and like Miss X in appendix 1. It would appear appropriate to consider the questions below as a starter for discussion, debate and eventually a specific care pathway for people with PMLD who require acute hospital admission at this time. This may in fact also be useful for a care pathway post this current situation.

Families are really keen to support the right decisions being made, at the right time, by the right practitioners that then enables their children to receive the right care in the right place.