# **“When can I hug my son?” – compassionate visiting in care/residential homes/supported living.**

## **BACKGROUND**

PAMIS, Promoting A More Inclusive Society, solely supports people with profound learning and multiple disabilities (PMLD) and their families to lead healthy, valued and included lives. With 28 years’ experience in family support, inclusive practice, learning and development, research and campaigning, PAMIS understand the complexity of care and support required by this group

People with PMLD and their families are some of the most excluded within our communities, and currently some of the most isolated. A person with PMLD has a profound learning disability and will also have multiple complex co-morbidities. These may include: a life limiting condition; no verbal communication; wheelchair users; doubly incontinent; hearing and visually impaired; epileptic; gastrostomy fed and possible respiratory problems requiring suctioning and oxygen. However this group also contribute to the lives of the people they engage with and are sons, daughters, siblings and part of a whole family. For some people home is not within the family home and they are living in supported accommodation, residential or care homes. However in these situations family carers still play an important role in the lives of their relative, emotionally, socially and physically and therefore should be seen as frontline carers.

For people with PMLD living in care/residential homes or supported living, and their families, COVID has torn them apart. Since first lockdown in March 2020 there has been no opportunity to have family time or physical contact which is so important when individuals have sensory deficits and when a hug conveys the meaning of love.

## **ISSUE**

The Scottish Governments Covid19 restrictions are denying family members who suffer from learning disabilities who live in care homes/supported accommodation settings proper and fair access to their families. Those individuals who have a severe-profound learning and multiple disabilities remain invisible to the Scottish Government and therefore the blanket approach and guidance to visiting and indeed many other CPVID 19 guidance does not take into account the specific emotional, sensory and cognitive needs of this group. The denial of access to their families is causing real harm to both them and their family carers. Risk assessments of the detrimental effect on their mental health are not being undertaken as suggested by Scottish Government and the implementation of guidance is being left to local Health and Social Care Partnerships interpretation which currently pays no heed to the individual human rights, circumstances and health of individuals. They are being denied their right to a family life by these restrictions, which are causing real harm to them and to their families.

This group of people are the only group who are being denied any freedoms. Even those shielding have resumed a new normal life in the community.

Many family carers have been self-isolating in order to enable them to visit and support their relative and are unclear as to why they, as part of the care team, cannot have the same close access to their relative as a paid care can who may well have been abroad/to the pub/attended social gatherings. They are willing to undergo the same testing as a paid carer but currently this option is not even being explored.

## **IMPACT**

While some impacts of this policy might not be obvious until some point in the future very real impacts are being felt in the here and now which must be addressed as a matter of urgency. These relate not just to the individual with PMLD but also to their family carer. These include:

* Emotional distress
* Mental Health decline -
* Physical Health decline
* Future life limitations including morbidity

Noticing and understanding the decline in mental wellbeing in someone with PMLD requires expertise and there is growing concern that the mental wellbeing of this group is not being monitored or is being ignored. The opportunity to personalise approaches following a risk assessment of the mental and physical wellbeing appear to be ignored and we question how many risk assessments are/have been carried out. Each person who lives in these settings should be provided with an individual risk assessment and not assessed with a blanket policy. They are a group of people with individual health status, individual capacities, wide ranging abilities and cannot be treated as one amorphous group.

We know of one family who has shared their experience of being able to see their relative when her mental health was seen to be in decline. These “normal” visits home have made a huge difference to her mental wellbeing and one wonders that if one agency can support this why this personalised approach cannot be used in other areas/settings.

## **ASKS**

Our key ask is that:

1. The role of family carers is seen not as visitors but as an integral part of a person’s care team. This would enable family carers to immediately access their relative within a care home/supported accommodation. The care and emotional support provided by family carers is an essential component of the health and wellbeing of the person with PMLD. Family carers have been offering to follow the same protocols as paid carers but this has not been followed up by Scottish Government or locally.

There are examples that would support this approach in Ontario (<http://health.gov.on.ca/en/pro/programs/ltc/docs/covid-19/mltc_visitor_policy_20200909_en.pdf> )

And Ireland (<https://www.hpsc.ie/a-z/respiratory/coronavirus/novelcoronavirus/guidance/infectionpreventionandcontrolguidance/residentialcarefacilities/Guidance%20on%20visiting%20residential%20facilities.pdf> )

If this is supported our second ask would not be required as testing would be part and parcel of being seen as part of the care team.

1. Current and future testing facilities should be made available to family members as a matter of urgency in order to facilitate what is really important for our loved ones, which is to be allowed access to their families and freedom to visit family at home. As testing methods improve family members should be at the forefront as well as care workers.

However we also ask that:

1. Scottish government engages with family carers and third sector organisations that support this group to collaboratively work together to develop guidance that specifically addresses the needs of this invisible group and that calls for individualised risk assessment which takes into account their mental and physical wellbeing and the family carer situations.
2. This group of people are considered within all guidance as a unique group and not see within the context for e.g. of older people. They will require additional considerations and this should be highlighted within the equality impact assessments undertaken.
3. Health and social care partnerships engage with family carers and third sector organisations that support this group, to collaboratively work together on implementing guidance.

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