

# Mothers with Acquired Brain Injury (Including Stroke)

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Best practice considerations  
for the health service



# Best Practice Considerations for the Health Service: Working with Mothers with Acquired Brain Injury, including Stroke.

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*With special thanks to the co-researchers who gave willingly of their experience and their time*

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## Introduction

This document was developed from a PhD study, exploring the lived experience and support needs of mothers with Acquired Brain Injury (ABI) and their families. There is a significant gap in the research on mothers and women with ABI, largely due to the larger proportion of men who acquire brain injuries (Colantonio, 2016; Hyder *et al.* 2007). The study set out to address this gap, attempting to shed light on the impact of ABI on mothers and their families, while also challenging the omission of mothers from parental brain injury research, seeking to give these mothers a voice. A Feminist Participatory Action Research (FPAR)<sup>1</sup> framework was utilised, using qualitative research methods. With ethical approval from the National Rehabilitation Hospital (NRH), Headway, and University College Dublin (UCD), the study posed two research questions: 1) How do mothers with ABI perceive the impact of their ABI on themselves and their families?; and 2) How can mothers with ABI and their families be best supported by healthcare professionals (HCPs)?

This document incorporates both practical suggestions for HCPs and broader suggestions for health and social policy.

1. For more information on FPAR, see for example, Reid and Frisby (2008) Finding the 'Action' in Feminist Participatory Action Research or Johnson and Flynn (2021) Collaboration for Improving Social Work Practice: The Promise of Feminist Participatory Action Research

## Methodology

The study had three action research cycles.

**Cycle One:** involved conducting narrative interviews with 10 women who were mothers before they had their brain injury. These women were recruited through the NRH and Headway, two of the leading organisations working with adults with brain injury in Ireland.

**Cycle Two:** involved facilitating a Co-Operative Inquiry<sup>2</sup> group with a sample of the 10 mothers from Cycle One. The purpose of this group was for the participants to discuss the support needs of mothers with ABI, and to have an opportunity to have a voice and make an improvement to the service offered to women with brain injuries.

**Cycle Three:** involved development and dissemination of suggestions, in the form of this document 'Best Practice Considerations', that can be used by HCPs when working with mothers with an ABI, promoting the needs of this client group and ensuring their unique situations are considered and supported. While the document reflects the suggestions of the participants in the Co-Operative Inquiry group, some ideas were further developed by the author.

2. For more information on Co-Operative Inquiry groups see Short and Healy (2017) Writing 'with' not 'about': Examples in co-operative inquiry

The Co-Operative Inquiry group comprised five of the women who had been interviewed in Cycle One of this research. The author facilitated the group together with a Senior Speech and Language Therapist from the NRH. Six meetings were held in total, running every second week from October to December 2023. The sessions were hybrid, with some people present in person and some online via the Teams platform.

The leaflet was presented to Headway and the NRH as part of the action research study. Meetings were held with representatives from both organisations to discuss the document, but also to look at ways in which the services they provide to mothers with ABI and their families could be improved upon.



## Practice Considerations

### 1. *Awareness of the unique experience and support needs of mothers with ABI*

The following recommendations were made by the group in terms of recognising the unique experience of mothers with an ABI, and their subsequent support needs.

- HCPs should be mindful that mothers may feel the need to mask hidden impairments or sequelae due to childcare pressures and, bearing this in mind, should strive to ensure that a thorough assessment of support needs is conducted.
- HCPs should acknowledge the challenges for mothers at all stages of their children's life cycle<sup>3</sup>. For example, mothers of toddlers may need support with performing childcare tasks while mothers of teenagers may need support with providing emotional support to their children.
- HCPs should consider running a support group specifically for mothers with the following criteria:
  - ◊ Available to mothers who are at least six months post-injury;
  - ◊ Open group – people can join at any time;
  - ◊ Ongoing long term group, run fortnightly or monthly;
  - ◊ Hybrid – in person and virtual options;
  - ◊ Facilitated by 2 members of an interdisciplinary team;
  - ◊ Have 'experts by experience' available to speak to the group;

3. For more information on children's understanding of brain injury at all stages of their development, see for example Daisley et al. (2009) Head Injury: the Facts

- ◇ Have an educational session on the compassion focused model<sup>4</sup> to encourage self-compassion.

## 2. Support for children of mothers with ABI

The group recognised that other members of their family, particularly their children, were effected by their brain injury and needed support. They made the following recommendations:

- HCPs should give more recognition of the impact of ABI on adults under 65, and take a systemic approach, assessing the needs of families as well as the person with the ABI;
- HCPs should provide support to children of mothers with ABI, in the form of psychological or psychoeducation support or peer support groups;
- Due to the lifelong nature of ABI, support should not be restricted to the immediate aftermath of the injury, but rather children should be offered support as and when they need it<sup>5</sup>.

## 3. Ongoing rehabilitation support after the acute phase

The need for ongoing rehabilitation after the acute hospital phase, and in some cases, after the initial rehabilitation phase, was recommended by the group. The group felt that there should be an acknowledgement by the health service in particular of the lifelong impact of ABI and the need to offer ongoing support. These are reflected in the following recommendations:

- In addition to their neurological reviews, mothers should be given the opportunity to have holistic six- monthly check-ins with HCPs, such as Social Workers and Psychologists, to assess how they are coping practically and psychologically with their ABI;
- HCPs should provide more information on services available after brain injury, how to manage at home, what to expect in terms of challenges and recovery;
- Referrals should be made to ABI specific<sup>6</sup> services irrespective of level of impairment;
- Rehabilitation professionals should recognise the importance of rest and self-care as well as rehabilitation activities. They should encourage engagement in rehabilitation but acknowledge the importance of rest in order to avoid putting pressure on people to constantly strive to reach goals;
- Rehabilitation professionals should give realistic hope and expectations, finding the right balance between giving hope for recovery with the reality of the long term implications of brain injury, for both the mother and her family<sup>7</sup>;
- HCPs should acknowledge and validate mothers' experiences, assessing all symptoms and sequelae in the context of brain injury before assigning the cause to stress or anxiety.

4. Gilbert, P. (2009). Introducing compassion-focused therapy. *Advances in Psychiatric Treatment*, 15(3), 199-208.  
 5. For suggestions on how to support children of parents with ABI see 'Supporting Child Relatives of Adults with Acquired Brain Injury: A Resource for Rehabilitation Teams', NRH 2018

6. [www.nrh.ie](http://www.nrh.ie); [www.headway.ie](http://www.headway.ie); [www.abiireland.ie](http://www.abiireland.ie)  
 7. Clark-Wilson and Holloway (2020) *Family Experience of Brain Injury: Surviving, Coping, Adjusting*

## Policy Considerations

### 1. Education and training for healthcare professionals (particularly in acute hospital settings)

The group felt that there is a lack of awareness and understanding by healthcare professionals, particularly in acute hospital settings, of the impact of hidden sequelae of ABI, such as fatigue and reduced information processing speed. They recommended further education is needed.

- HCPs should be given education on all sequelae of brain injury, particularly hidden challenges, during their training but also as part of their Continuing Professional Development (CPD).
- Modules on brain injury should be included in health and social care professionals, medical and nursing training courses.
- CPD modules on brain injury should be made available to healthcare professionals.

### 2. Public awareness campaigns on the hidden nature of ABI

The group noted the lack of public awareness of the sequelae of ABI, particularly hidden challenges such as fatigue and information processing difficulties. They recommended a public awareness campaign, in which the public could be educated and therefore more understanding of the challenges. In particular, they suggested:

- The distribution of leaflets and other media exposure to highlight hidden disability sequelae such as fatigue and sensory overload;
- Guidance to the public on how to recognise the sequelae of ABI and how best to support individuals;

- Advice to the public about making assumptions that physical recovery means full recovery, acknowledging the hidden sequelae and long term impact of ABI, both cognitively and emotionally<sup>8</sup>.

### 3. Supporting Return to Work

Some of the group had difficult experiences with their employers when trying to return to work after their brain injury. They had the following two recommendations, which they suggested would help:

- Employers should offer phased return to work options, particularly when recommended by Medical Consultants, Occupational Health departments, or Occupational Therapists;
- Employers should use a rights based and compassion focused approach to those returning to work after an ABI, recognising the potential challenges and adapting the work environment to accommodate these challenges.

### 4. Support for Mothers

Mothers with ABI are a group with distinctive needs, particularly in terms of the expectations of motherhood and the roles and responsibilities they continue to have, while also trying to cope with the effects of their injury. The following recommendations may assist them in their recovery:

- Respite or financial assistance should be made available to mothers to assist with childcare in order to support recuperation and recovery;

<sup>8</sup>. See [www.brainline.org](http://www.brainline.org) for more information and resources



- HCPs should offer a tailored and timely service to support mothers at specific periods of their life (for example, transition of their child to secondary school or returning to work while also managing childcare);
- The health service should offer home based rehabilitation and support, for example, to help mothers manage life skills such as cooking or childcare.



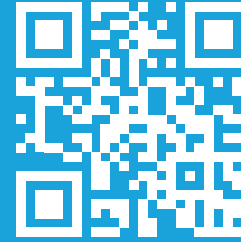
## Conclusion

This document represents the perspectives of a sample of mothers who are living with an ABI in Ireland. Through their engagement as co-researchers in a PhD study, which explored the lived experience and support needs of mothers with ABI, they have outlined areas in which they consider healthcare practice could be improved upon in order to ensure the needs of mothers with ABI and their families are met. It is hoped that this document could be a starting point for services to evaluate their practice and consider areas for improvement.

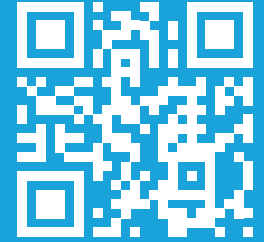


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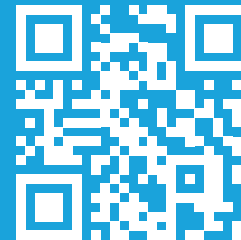
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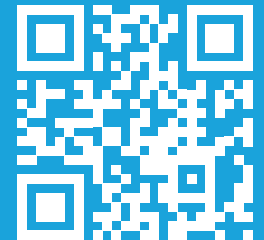
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[www.abiireland.ie](http://www.abiireland.ie)



[www.headway.ie](http://www.headway.ie)



[www.nrh.ie](http://www.nrh.ie)



