Families’ experiences of life in the year after a child’s critical illness: Navigating the road to a ‘new normal’. R1

**Authors**

Ellie K Atkins DClinPsych, Paediatric Psychology Service, St George’s University Hospitals NHS Foundation Trust, London, UK

[ellie.atkins@stgeorges.nhs.uk](mailto:ellie.atkins@stgeorges.nhs.uk)

Mary John MSc, School of Psychology, University of Surrey, UK

[m.john@surrey.ac.uk](mailto:m.john@surrey.ac.uk)

Gillian Colville MPhil, Paediatric Psychology Service, St George’s University Hospitals NHS Foundation Trust, London, UK

[gcolvill@sgul.ac.uk](mailto:gcolvill@sgul.ac.uk)

**Corresponding Author**

Gillian Colville, Paediatric Psychology Department, 2nd Floor, Lanesborough wing, St George’s Hospital, London SW17 0QT, UK.

Email gcolvill@sgul.ac.uk[gcolvill@sgul.ac.uk](mailto:gcolvill@sgul.ac.uk)

Telephone: 0208 725 2214

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# ABSTRACT

Semi-structured interviews were carried out with patients and family members (n=18) post-discharge, to examine how they managed their recovery in the year following a child’s intensive care admission. Data were analysed using Grounded Theory. Participants described an ongoing need to develop and adapt their narratives about admission and recovery. Other key themes were: just getting through; recognising they had changed; striving for normality and finding positive aspects related to their experiences. Ittook longer than they expected for families to build a coherent narrative of events post-discharge and adjust to the ‘new normal’. Implications for health professionals are discussed.

(99 words)

# INTRODUCTION

The field of intensive care medicine has long endeavoured to maintain a family-centred focus, by involving families in the daily care and decision-making regarding treatment options. More recently, as survival rates have improved, there has also been a growing appreciation of the importance of establishing information and service needs directly from patients and caregivers in the longer term. [1] Children treated in a Pediatric Intensive Care Unit (PICU) may be traumatised by their experience of numerous painful and invasive procedures such as artificial ventilation and repeated venepunctures in relation to their treatment for life threatening conditions including cancer, congenital heart problems and respiratory difficulties secondary to prematurity. Others find themselves in PICU after serious road accidents, with life altering injuries. Parents have to negotiate the demanding experience of watching their child’s suffering, fearing the worst and at the same time having to balance the needs of their other children and of keeping the household running.

A recent review of research priorities in the field of pediatric intensive care [2] has highlighted the need for a better understanding of how children recover after a critical care hospitalisation, in order to improve their longer term care. Furthermore the development of a framework to understand the pediatric version of Post Intensive Care Syndrome (PICS-p)[3] has emphasised the importance of considering the whole family unit, in relation to examining outcomes.

There are now a number of quantitative studies showing that a significant proportion of children and parents report clinical levels of distress in the early months after discharge.[4-7] A review of 27 studies of pediatric critical illness survivors notes significant levels of post-traumatic stress symptoms in 10-28% of children,[8] with 18-48% of parents also reporting these symptoms post-discharge.[9] Children who require painful or invasive procedures are more likely to develop trauma symptoms after the event,[10] as are those with delusional experiences, such as hallucinations, during admission.[11] However in the main, children’s memories of PICU are neutral or positive,[12] and although parents’ perception of threat to life during admission is related to later difficulties,[4] neither severity of illness or length of stay have been found to be systematically associated with long-term distress.[13]

Also, although it is known that a significant minority of children and parents appear to be distressed by their experiences, it is unclear what maintains or ameliorates this distress in the recovery phase or how the majority cope. There are a small number of qualitative studies in this field but some only describe particular disease subgroups, [14,15] and most address experiences during admission or soon after discharge, with parents identifying vivid memories and worrying about whether there might be a long term impact on their child, while children expressing difficulty remembering what happened. [16-18] Only a couple of studies have explored family members’ longer term experiences, raising issues about the difficulty children report integrating what happened into the their sense of self [19] and a preoccupation, for all family members, with trying to get back to normal, even years later.[20] In summary, little is known about how families manage in the year following admission, despite calls for more research into the *long-term* psychological impact of critical illness. [14,21

# Study aims: This study aimed to add to the literature on the psychological impact on families of a PICU admission by describing families’ lived experience of over the first year post-discharge. A companion paper sought to examine the degree to which a biopsychosocial model was helpful in explaining the different phases of the families’ recovery trajectories. [22] The focus of the analyses presented in this paper is on the processes and strategies they found helpful on their journey.

It was further hoped that by gathering qualitative data on the experiences of a range of families in this situation, and by capturing both child and parent perspectives, it would be possible to develop some written guidance on this topic for other families. Finally it was hoped that the understanding gained from this information might also help inform future interventions designed to support children and families following PICU admission.

# METHOD

Ethical approval for the study was granted from the local NHS Research Ethics Committee (REC no 09/H0801/22).

**Participants:** Families who met the inclusion criteria within a specified time period (May 2009 to February 2010) were invited to participate. Inclusion criteria were a stay of more than 24 hours; child aged 5-16y at the time of admission; admission in the previous 8-18 months and biological parent available to take part. Children who were admitted for a non-accidental injury or palliative care were excluded – the former because these children were subsequently separated from their families, and the latter so as not to burden their parents at such a difficult time.

In total, 48 families met the inclusion criteria Their primary care providers were contacted to request consent to contact the family. This was only refused where the child had died (n=3) or where the primary care provided considered it inappropriate to contact the family because of the pressures they were under related to managing the child’s health problems at the time (n=1). Of the 44 families approached, three were not contactable as they had changed address. Of the remaining 41 families, 11 initially agreed to take part but two dropped out before interview. The remainder did not respond to a reminder about the study and were therefore deemed to have declined. A summary of the main characteristics of the 18 participants, from the nine families who agreed to take part, is provided in Table 1. (The children have been given pseudonyms to ensure their anonymity and confidentiality.)

**Design**: Families were interviewed in their homes at a time convenient to them. Parents signed a consent form and children an assent form. Both were informed of their right to withdraw at any point during the interview, or later in the study. Children were given age appropriate literature to support them in making a decision to participate in the study. Children and parents were interviewed separately or together, depending on their preferences. A semi-structured interview schedule was created, based on the literature and clinical experience of the researchers. It consisted of open-ended questions and evolved over the course of the study, in keeping with Grounded Theory methodology (see below). For children under the age of 12y, the interview schedule was augmented with related activities such as hospital play with small world figures and hospital beds and drawing materials, with the aim of making the interview interactive and enjoyable for the child. Interviews ranged in length from 60 to 150 minutes and were tape recorded and later transcribed verbatim by the lead researcher EA. All families were of White British ethnicity except one, who identified as Asian British.

**Qualitative Analyses*:*** The data were analysed using Grounded Theory [23], a rigorous qualitative methodology [24]. Repeated readings of the transcripts were carried out by the lead researcher EA, who highlighted meaningful coding units. Labels were then provided for these, in the initial coding stage, by all three authors. The interview schedules were adapted as new coding labels emerged. Further interviews were then carried out, until such time as saturation was reached, in the sense that no new codes were emerging. Once the interviews were complete, core ‘conceptually refined’ categories were identified which had major explanatory power. An independent rater then reviewed these main themes and matched them with the raw text to ensure that they adequately fitted the data and to check that were endorsed by all participating families. Finally, participants were invited to review a summary of the findings and to provide additional comments, from their perspective. Four parents and two children provided additional written feedback on forms provided with this summary.

# FINDINGS

During the interviews participants were asked about their experiences post-discharge. However, without exception, they needed to talk, in depth, about their memories of the PICU admission itself. This therefore emerged as a key organiser to people’s reflections on recovery. The admission was experienced as terrifying and a disruption to all normal routines and expectations:

*“I have this image...the sword of Damocles waiting over your head to strike your child down and then, when we were coming back in the taxi, I felt we’d got out, (cries) but we knew there were others that didn’t.”* (Mother of James, 17y)

Parents and young people described having no control over what was happening to them at this time and that their relationships with wider family and friends were significantly disrupted. Even during admission, families sought ‘normality’ by attempting to do activities, that they would usually do at home, such as playing, watching TV and playing computer games, but found these very challenging due to factors such as lack of physical strength and stamina, constant interruptions from medical staff and a busy and distracting environment .

*“You feel pretty rotten as it is, because you can’t keep normal life going, do the things you would normally do...”* (Father of Jack, 5y)

Participants then shared their experiences post-discharge, which fell into the following five major themes. These were raised by all participants in varying degrees and are discussed in turn below.

### Just getting through

Families reflected that, whilst in hospital, they did not have space or time to think about, let alone understand, what they were going through and they became aware of this forcefully when they came home. When the child was first discharged from hospital, both parents and children needed to recover physically and reintegrate, initially within the wider family and later with colleagues and friends, at work and at school. Early coping strategies functioned to provide a useful buffer – a way to avoid thinking about what had happened until they were more ready to deal with it.

*“Just being positive…just trying to stay positive, just being focused and just believing that you’re going to get there. You have to. You have to believe.”* (Mother of Yvonne, 16y).

*“ She went through a whole phase of comfort eating, put on a load of weight….. I think that was a way of coping.”*(Mother of Ciara, 15y).

Ways of managing this early period were varied and included throwing themselves into work/school work, keeping busy, thinking positively and detaching. These strategies remained important throughout the recovery process, but over time were replaced by more reflection, which was more effective in directly addressing life after discharge, allowing space for new narratives to be acknowledged and integrated.

### A changed person

The hospital admission represented a challenge, both to how parents and children viewed themselves, and how they related to others. Several parents acknowledged that they had become more protective.:

*“I wanted to wrap her up in bubble wrap and know exactly where you were every second of your life” (Mother to Ciara, 15y)*

The young people’s experience of illness and PICU admission had a significant impact on the evolution of their identities. As they recovered physically, they had more time and energy to reflect on how they had been affected by what had happened:

*“I’m normally a very confident person ... I went down there and I couldn’t walk in. I just couldn’t do it, just ‘cause my confidence took a massive knock…I’m used to being one of the clever people, and everyone knew more than me.”* (James, 17y)

Participants found they needed to work to understand the changes which had happened to them as a result of their critical illness and needed to understand these changes in the context of their PICU experiences, but in addition began to notice, over the year, that their interests were also changing naturally, as they returned to the normal tasks of development:

*“I used to like dying my hair and listening to rock music and emo, and now I’m into R&B and stuff like that. Quite a lot has changed for me”* (Ciara, 15y)

### Striving for normality

After discharge, families assumed that life would return to ‘normal’, in the sense that life would go back to how it was before. Participants emphasised how long the process of ‘getting back to normal’ was taking them and their frustration with this.

*“We’re still trying to achieve it [normality] now” (*Father of Tim, 5y)

*“...getting stronger but not strong enough to do anything on my own. It was very frustrating…. there wasn’t anything that could be done about it either”* (Yvonne, 16y)

The reality was that life did not return to the pre-admission status-quo in a smooth or immediate way and, in fact, some things were never the same again.

Whilst normality was craved by all families, they gradually became aware that the experience of a serious and life-threatening illness had significantly changed them and the direction their lives had been going in. They also began to realise that ‘normality’, as it had been construed before the experience, was no longer achievable and so it was that seeking a *new* normality became a key task for them.

*“It’s like BC and AD, you know ‘life before’ hospital and ‘life after’, since all that happened”* (Mother of Thomas, 6y)

### Developing a narrative

Throughout the interviews it was clear that both young people and parents needed to tell their story, in order to process what had happened to them.

*“I remember when I was asleep for six sleeps.”* (Jack, 5y)

*“You get more time to think about it, so you dwell on it to a certain extent and you think ‘My God, this is what happened!’”* (Father of Jack, 5y)

Parents and children reported that there was little opportunity to share their narrative with others. They described a number of barriers to talking about their experience, including the fear of upsetting others and having a disjointed or incomplete memory of what had happened.

*“It’s pretty hard. You know you can’t imagine it until you...you see it on films, but until it happens...” (Father of Ella, 11y}*

Creating narratives was an ongoing, organic process in which families continued to engage. Indeed, this creating and re-authoring of narratives seemed to be an important part of the recovery process. It was apparent that once they had put their story together, they felt they had more control and ownership over what had happened to them.

*“ I feel like if me and my mum told the story together people would, like, understand it more, because Mum was there to see me, (what I don’t remember) and then I know the things mum doesn’t know, going on in my head, and things like that and if you put the two stories together, people might understand it more”* (Ciara, 15y)

1. **Positive growth experiences during recovery**

Families noted that they reached a turning-point in their journey, moving from ‘just coping’ to ‘recovering’. This included the recognition that although life was different now, it could go on and continue to be positive, despite their traumatic experiences.

*“Going through this experience can have a positive effect on people. It can make you stronger as a person and to appreciate the smaller things in life. In your recovery you look back and realise what you’ve overcome and that’s a wonderful feeling”* (Yvonne, 16y, written feedback).

*“You’ve blossomed really. It’s made you a stronger person”* (Mother of Yvonne, 16y).

Many people talked about changing their priorities and having a new, enhanced perspective on life as a result of their experiences. These ideas about recovery meshed well with the changing identity people were describing and many embraced the idea that they had grown as a person, as they moved along their recovery journey.

*“It’s completely changed me... It’s made me a better person”* (Mother of Ella, 11y)

DISCUSSION

This study explored the recovery process for families, in the year following a PICU admission and investigated how they negotiated this experience. Grounded theory is particularly interested in ‘how and...why participants construct meanings...in specific situations’.[24] This research aimed to discover how participants came to find meaning in their experiences and why particular key tasks seemed to be instrumental in helping them achieve this. The data showed that it was only once they had a certain amount of temporal distance from the admission, that families really began to reflect on their identity in relation to their experiences in PICU and to work to create a coherent narrative. They were then able to understand more fully, both what they had gained, as well as what they had lost, as a result of the child’s period of critical illness, describing elements of post-traumatic growth as they sought to find meaning in their experiences. This is a phenomenon which has been described previously in this population [25]  and in other groups in health settings, such as parents with children with life-limiting conditions.[26]

**Model of recovery:** The processes families went through, as they recognised, and came to accept, how things had changed, were ongoing and dynamic and are illustrated diagramatically in Figure 1. This model makes explicit how families described moving from coping to recovery, as they engaged in the cognitive work required to process what had happened and advance along the recovery pathway. The stages described were not discrete, however, with participants reporting that they moved between stages in a fluid way, sometimes moving backwards after a setback, and at other times engaging in two processes at once. In this respect there were similarities with the way grieving people have been observed to shift back and forth between focusing on their past loss and the need to build a new future, as observed in the ‘Dual Process’ model of coping with bereavement, which describes the way people naturally ‘oscillate’ between these two perspectives.[27]

This was due to a number of issues including the depletion in energy related to the management of the child’s ongoing medical difficulties and their various needs to process what had happened emotionally, recover their sense of self, accept a change in identity and integrate their understanding of the experience of living through the child’s critical illness into this new identity. In relation to this it was clear that, even during the interviews, people were still actively working to construct a narrative of their experience a year on, reflecting the social constructivist nature of this qualitative approach, where meaning continues to be developed through conversations. This task of creating a narrative appeared to be instrumental in helping families move to a position where they could better accept the ‘new normal’.

**The importance of developing a narrative**: Creating a narrative of the events associated with PICU admission seemed important for all the participants in this study, although they did not realise this at first, when the focus was, of necessity, primarily on the child’s *physical* recovery. [22] They then expected to reconnect with their life and expressed a desire at this stage to put the PICU experience behind them, so it came as a shock when they realised that they still had a long way to go before they could say they had fully ‘recovered’ as a family. Over time, this cognitive dissonance (ie the mismatch between how they felt and how they expected to feel) prompted them to reflect further on their experiences, as has been described in other trauma exposed populations [28,29] and, in doing so they began to build a coherent narrative of events. It also seemed to be important, however, that they shared their memories in order to integrate their different stories. As Manning et al.[19] have observed, children can be distressed by the gaps in their memory for events in this situation and by the differences between their narratives and those of other family members.

This finding is consistent with the recent interest in the potential for intensive care diaries to help aid memory and understanding, post-discharge. [30] Work with adult intensive care survivors [31,32] has identified the importance to these patients of developing a narrative, during and following intensive care admission, with the use of diaries reported to be associated with reductions in subsequent psychological distress in both patients [33,34] and caregivers. [35] Diaries are also beginning to be used more often in pediatric settings [36] with one recent qualitative study finding that they are much appreciated by families because of the way they ‘support the children in understanding and sharing their story’. [37]

Furthermore, a recent case series has shown the value of a *narrative* approach for helping parents with PTSD related to their child’s PICU admission, [38] although the authors stress in this study that is was important, therapeutically, to wait until parents were sufficiently emotionally robust - which was usually only once the child was sufficiently recovered physically - before this treatment could begin.

**Clinical Implications**: These research findings are likely to be useful for health professionals to be aware of, in their dealings with families, whether this contact is acute, or later on in primary care. Carnevale has argued that PICU families need more help, post-discharge, to developing strategies to manage what he describes as ‘their central struggle’ to recapture their ‘previous life’. [20] Provision of the information such as that provided by this study may go some way towards helping to manage their expectations as to how realistic this aim is, suggesting instead that they might find it easier to come to accept a *new* normality and encouraging them to create a narrative to help them to move on.

The main points to consider as part of guidance to families, where appropriate to manage their expectations of recovery are 1) that psychosocial adaptation usually only begins after the child has largely recovered physically; 2) there is value in communicating with each other to put their story together about what happened; 3) that with time and resources, including their own natural resilience, most will make a good recovery and move on, but 4) that this journey may take longer than they initially expect. Finally, 5) the concepts of the ‘old normal’ and the ‘*new* normal’ may be helpful to families.

The illustrated leaflet generated from this research could also be useful clinically, either directly as an aid to families on discharge, or indirectly as a prompt and source of information for clinicians. In this booklet (which is freely available online, [39 and is currently also being translated into Spanish) the main themes reported by families are interwoven with advice from clinical psychologists with extensive experience of supporting families during and after PICU admission. The text draws on their frequently mentioned metaphor of recovery as a journey, and includes a pictorial ‘roadmap’ (see Fig 2) as well as guidance about how to manage particular challenges (‘roadblocks’) they might encounter along the way. Examples of these ‘roadblocks’ are trying to make sense of what happened too early, at a time when a family member is not ready emotionally, and finding it difficult to make conversation with a child who is reluctant to talk about what happened.

**Research implications**: Further qualitative work with larger, more representative groups, and particularly with parents of younger children (who make up the majority of referrals to PICU), is needed. Also with regard to intervention research, given their emphasis on what families describe as their need to put their story together, it may be that approaches designed to provide assistance with this particular task would promote earlier psychological adaptation. The COPE intervention, which sought to empower mothers to communicate with children about their PICU admission, has been found to be associated with lower rates of distress in parents and children, and fewer behaviour difficulties in children, a year after discharge. [40] Also, the finding that rates of post-traumatic stress were higher at a year post-discharge in families where children were more avoidant about discussing their experiences,[6] provides further evidence that this might be a fruitful area in which to intervene. Another avenue for future research could be the evaluation of the use of contemporaneous diaries with families in PICU settings, which may assist with later story-making, post-discharge, and thereby facilitate psychological recovery sooner.

**Strengths and Limitations**: A strength of this study is that is provides information from children *and* parents, whereas most other qualitative studies have been restricted to the perspective of one or other group. Also it adds to the literature in that it focuses on the process of long term recovery, rather than just on experiences during admission. Furthermore, although sampling was not truly purposive, saturation was reached (ie. no new codes emerged in the final interviews).

However, it was not possible to compare participants with non-participants because of the ethical requirement not to store information on non-participants and the fact that only families of children aged over 5y were included may mean that the views expressed are not representative of families of younger children. A further limitation concerns the under-representation of ethnic minority families, which is important given reports in the literature of ethnic minority status being associated with more communication problems and greater distress in parents of sick children[41] and more generally, being a risk factor for PTSD. [42] Also. only three of the families interviewed had children with chronic conditions. This subgroup of patients, who have repeated admissions, make up an increasing proportion of the PICU population [43] and their families report different experiences during hospitalisation.[15]  It is also possible that the contributions of families were influenced in some way by whether or not children and parents were interviewed separately or together, or by parental education or socioeconomic status, the details of which were not collected.

**Conclusions:** This research has highlighted the importance of narrative creation to bridge the gap between families’ lives pre-admission and the ‘new normal’ state, in which they find themselves, after discharge.

Most families will manage without presenting to services for professional support but the information gathered in this study may enable health professionals, who are involved with the child’s care, to help them on their journey, by managing their expectations about the road ahead.

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Table 1: Participant information

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
| Pseudonym | Age when interviewed (years) | Reason for admission | Participants | | |
| Child | Father | Mother |
| Jack | 5 | Acute infection | ✓ | ✓ |  |
| James | 17 | Oncology | ✓ |  | ✓ |
| Yvonne | 16 | Oncology | ✓ |  | ✓ |
| Ella | 11 | Neurosurgery | ✓ | ✓ | ✓ |
| Tim | 5 | Neurology |  | ✓ | ✓ |
| Samuel | 10 | Neurology |  |  | ✓ |
| Ciara | 15 | Acute infection | ✓ |  | ✓ |
| Thomas | 6 | Elective surgery |  | ✓ | ✓ |
| Abbie | 9 | Elective surgery |  | ✓ | ✓ |

Figure 1: Model showing tasks along the pathway to accepting the ‘new normal

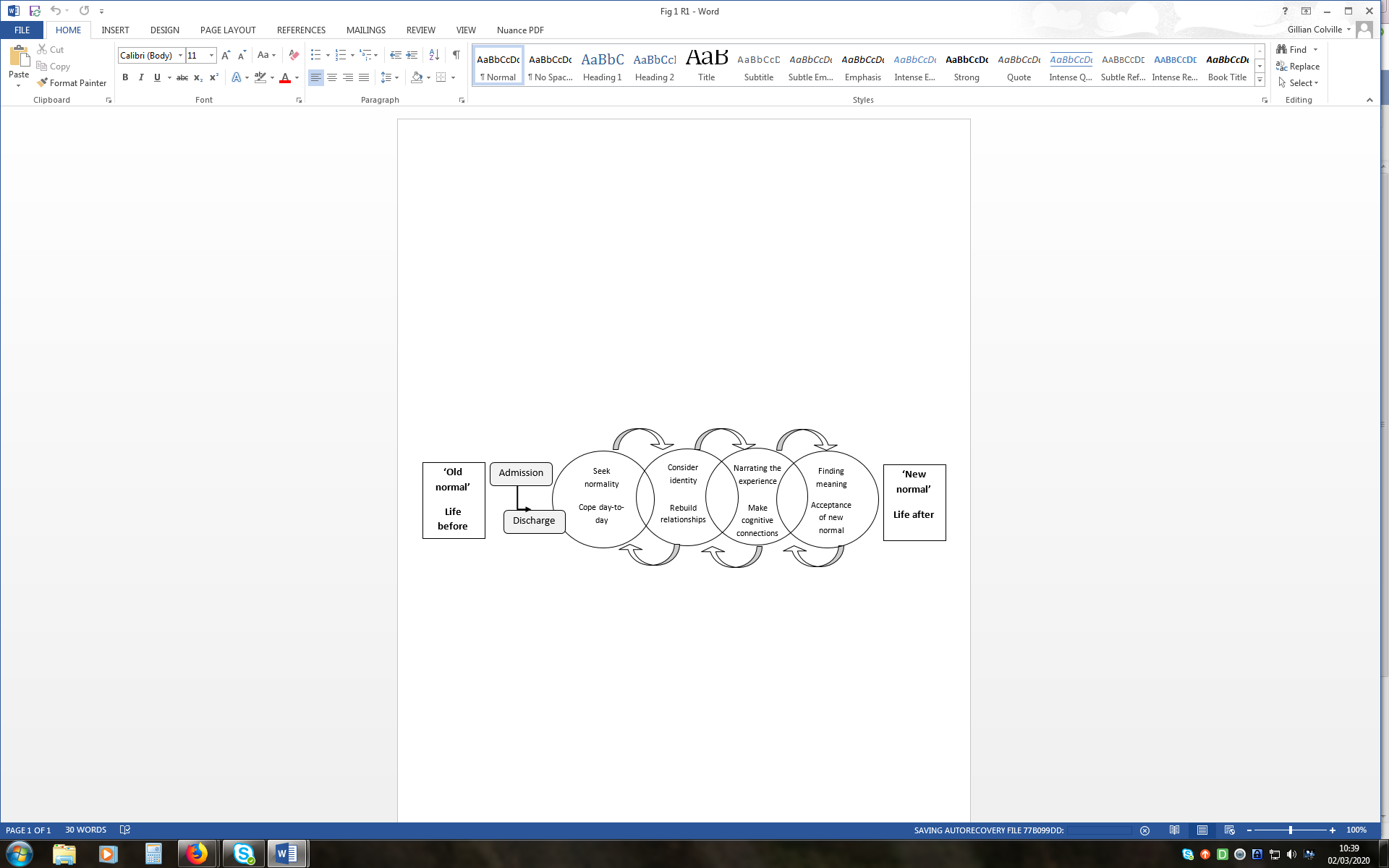
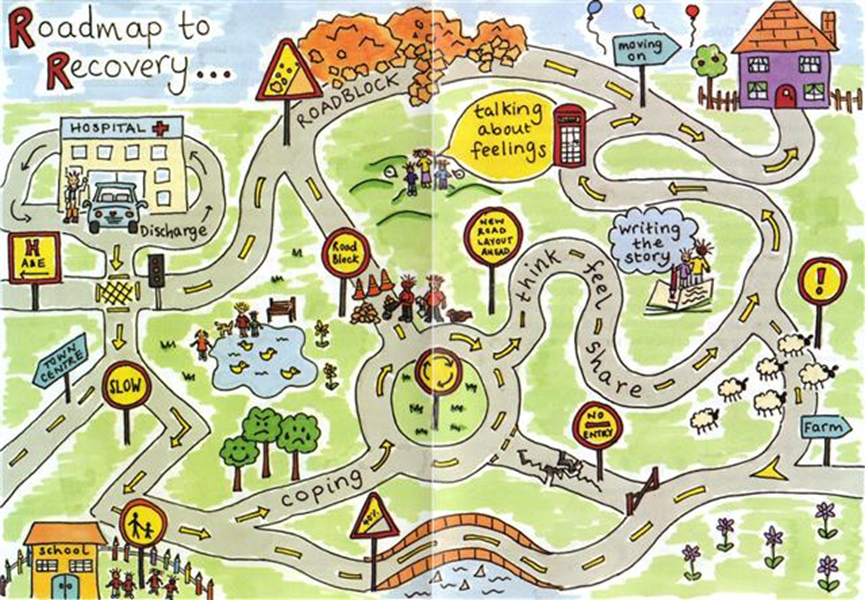


Figure 2: Illustration from leaflet for families showing a figurative recovery roadmap



**APPENDIX: INTERVIEW GUIDE**

**Family’s experiences of recovery following PICU**

1. **INTERVIEW WITH CHILD**
2. Can you tell me about yourself?
3. Tell me about what happened when you got ill/went into hospital
4. Experiences since hospitalisation

* Younger children (under 12y)

I have some questions about your feelings. (show stickers) what feeling is this person showing (show happy, sad, worried, scared faces).

Link to film strip: ‘This is a film script. I’d like you to draw a film that starts with your hospital experience and carries on until now. This will tell me about what your life has been like since you went into intensive care.’ Use as springboard for discussion

* Older children

I have some questions about what the last year has been like – thoughts and feelings. How have you managed? Positive and negative experiences and impacts? What stands out? How often do you think about the time when you were in hospital? How has your experience of being in hospital affected who you are now?

1. After having these experiences what advice would you give to another child who has to go into PICU?
2. Is there anything that you might not thought about before that has occurred to you during this interview? Is there anything else you think I should know to understand your experience better?
3. Do you have any questions for me? Is there anything you are worried about or not sure about? Do you have any feedback about this interview or how I could make it better?

*Equipment/activities available for use with younger children (under 12y): small world play figures and hospital bed; blank paper (with film-strip border) and coloured pencils;*

*stickers with faces showing different emotions*

1. **INTERVIEW WITH PARENTS (AFTER CHILD INTERVIEW)**
2. Can you start by telling me what X was like before going into PICU
3. Can you tell me about when X went into hospital
4. How, if at all, have your thoughts and feelings about X’s admission changed in the last year?
5. Looking back, what events in the past year stand out in your mind? Can you describe each one? How did this event affect how X has managed?
6. Can you describe the most important lessons you’ve learned in the last year?
7. What positive changes/negative changes have occurred in your life since X’s admission?
8. What/who has been most and least help during this time?
9. Tell me about the person X is now? What contributed to this change (or continuity)?
10. How well do you think your child has changed and coped? (at different points since discharge) Why?
11. Show parents their child’s filmscript and discuss – ask parent to elaborate. If child not interviewed discuss how they might share their experiences.
12. Can you tell me about X now
    1. Compare to pre-admission, and since discharge.
    2. Character changes?
    3. Any new fears/worries
    4. Strengths discovered
    5. Things they value since admission
13. How has the year been for you? Any strategies you’ve used? Have they worked?
14. What have been the easiest and hardest times since discharge? Why?
15. Is there any help you would have liked at the time or since?
16. Is there anything that you might not have thought about before that occurred to you during this interview?
17. Is there anything else that is important for me to know, to understand yours and your child’s experience better?
18. Do you have ny questions or comments for me?