

EMPATHIC CARE OF A PERSON WITH CEREBRAL PALSY: E-SIMULATION TOOLKIT



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INTRODUCTION

Empathy enhances healthcare professionals' understanding of the experiences, perspectives and needs of patients and colleagues (Zeighami et al, 2012; Petrucci et al, 2016). Consequently, it has become widely acknowledged as a vital component of professionalism (Fields et al, 2011), therapeutic relationships (Williams & Stickley, 2010) and person-centred care (Brunero et al, 2010). Empathy improves patient wellbeing, satisfaction and clinical outcomes (Petrucci et al, 2016), and also reduces the risk of healthcare staff experiencing stress and burn-out (Ward et al, 2012; Kelm et al, 2012). Importantly, empathy is an antecedent to cultural competence (Everson et al, 2015), and enables caregivers to respond appropriately and without prejudice to the needs and expectations of patients and colleagues, a number of whom will come from diverse backgrounds and/or vulnerable and groups.

Approximately 15% of patients admitted to hospital have a communication disability that affects their ability to speak with and/or understand the staff who care for them (Hemsley et al, 2016). A recent review of 27 studies identified that '...vulnerable patients with communication disabilities (i.e. impairments of body structure or function that impact upon speech, language, or communication function) face a three-fold increased risk of sustaining preventable and harmful patient safety incidents' (Hemsley et al, 2016, p. 502). Some of the most commonly reported factors include i) 'being in hospital with no way to gain the attention of or communicate with hospital staff'; ii) '...staff who are not always attentive even when patients raised the alarm'; iii) 'advocacy failure'; and iv) 'failing to listen, or to recognise complaints of pain or symptoms of distress' (Hemsley et al, 2016, p. 509).

The e-simulation described in this toolkit is designed to enhance healthcare students' and clinicians' understanding of and empathy towards people with cerebral palsy (CP) and complex communication needs. The e-simulation portrays Helen Ross' experiences of hospitalisation and aims to improve patient safety by raising awareness of the challenges that can be experienced by people with CP when interacting with healthcare professionals.

Authentic narratives have long been recognised as an effective means by which to engage learners (Garcia & Rossiter, 2010). Stories re-told from people's real-life experiences can awaken listener's empathic imagination and inspire them to consider ways in which to improve their future practice (Charon, 2006). However, some stories are challenging to tell, particularly when they belong to people who have complex communication needs or come from cultural and linguistically diverse backgrounds or minority or vulnerable groups. A shared ambition to enable one such a voice to be heard inspired the development of this e-simulation.

Cerebral palsy is just something I have; it is not a problem. My cerebral palsy is not my disability; society is my disability and sadly people's attitudes toward me. People automatically think I have a learning disability, just because I talk funny and I sit in a wheelchair. People just treat me like a child. ~ Helen Ross

ACKNOWLEDGMENTS



E-SIMULATION PROJECT TEAM

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The project team would like to acknowledge and thank Helen Ross for her willingness to share her personal story so that others might learn from her experiences. Sadly, Helen passed away in 2018 after a short illness just as this project was nearing completion.

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E-SIMULATION GUIDELINES & SESSION PLAN

LEARNING OUTCOMES

Participation in the 'Empathic care of a person with Cerebral Palsy' e-simulation will enable students to:

- Discuss the potential feelings, experiences and needs of a person with CP and/or complex communication needs
- Demonstrate an understanding of healthcare experiences viewed through the unique lens of a person with CP and/or complex communication needs
- Discuss the potential feelings and experiences of healthcare students and staff responsible for the care of people with CP and/or complex communication needs
- Reflect on how one's own perceptions, experiences, or stereotypical views might influence the care provided to people with CP and/or who have complex communication needs
- Discuss the relationship between empathy, person-centred care, therapeutic communication, dignity and patient safety for people with complex communication needs
- Reflect on how empathic healthcare interactions can influence the safety and wellbeing of people with CP and/or complex communication needs
- Discuss how communication and interpersonal skills can be adapted to ensure that each person's communication needs are appropriately met
- Discuss how completing the e-simulation will influence the care provided to people with CP and/or complex communication needs
- Develop personal learning goals for enhancing one's own knowledge and skills when caring for people with CP and/or complex communication needs.

Structure of the simulation

The e-simulation is approximately 60 minutes in duration including briefing, 7-minute film, and debrief. The film can be viewed on any computer or tablet device with audio and video capacity. Students can undertake this e-simulation as a classroom-based group activity or as an individual online learning activity.

Link to view or download the film titled 'Hospital admission: Hi! Morning, Helen', that forms part of the 'Empathic care of people with CP and complex communication needs' e-simulation toolkit: https://bournemouth.cloud.panopto.eu/Panopto/Pages/Viewer.aspx?id=506a71f8-657e-42e5-9ec0-a96500ac7b2c

PRE-BRIEF

The following information is to be provided to learners prior to watching the film:

The film titled 'Hi! Morning Helen!' is a reconstruction of a real-life event based on the hospitalisation experiences of Helen, a woman with CP and complex communication needs. It was Helen's hope that the insights gained from participating in this e-simulation might encourage healthcare students and clinicians to reflect on their own communication and interpersonal skills and consider how their attitudes and perceptions can influence the way they interact with and care for patients; particularly those from vulnerable and marginalised groups.

Please watch the film twice in order to consider and analyse the situation portrayed from the perspective of Helen and her nurse, Emma.

While viewing the film the first time, imagine you are Helen and 'put yourself in her shoes'. You have just arrived on a hospital ward following a fall at home where you sustained an injury to one of your legs and the wound requires treatment. You are in pain and waiting to be admitted. Think about and write down how Helen might have been feeling during the interaction with her nurses, Emma.

When you watch the film for a second time, put yourself in Emma's shoes. Imagine you have just started your shift and have been told during handover that you will be looking after Helen, a 42-year-old woman who has CP and complex communication needs. You have been asked to complete Helen's admission assessment. Think about and write down how Emma might be feeling.

The questions and activities incorporated at the end of the film are intended to promote reflection and discussion about how negative attitudes and stereotypes can influence the care of people with CP and/or complex communication needs.

After the film finishes and while waiting for the debrief do not to discuss the simulation or your responses to it. Spend this time reflecting on the situation portrayed from Helen and Emma's perspective and in consideration of their feelings and needs.

DEBRIEF

At the commencement of the debrief capture students' attention by providing these 'Four Fast Facts':

- 1. Approximately 15% of patients admitted to hospital have a communication disability that affects their ability to speak with and/or understand the staff who care for them (Hemsley et al, 2016).
- 2. Patients with communication disabilities (i.e. impairments of body structure or function that impact upon speech, language, or communication function) are at a high risk of adverse healthcare outcomes (Hemsley et al, 2016, p. 502).
- 3. Factors that increase risk for people with a communication disability include: healthcare professionals who do not respond when patients are concerned and failure to recognise complaints of pain (Hemsley et al, 2016).
- 4. An empathic approach can enhance healthcare professionals' understanding of the experiences, perspectives and needs of patients with CP and communication disabilities (Petrucci et al, 2016).).

Following the film a group debrief should be undertaken. The debrief is an integral component of the learning experience and fundamental to empathy development and attitudinal changes. Specific evidence-based strategies have incorporated into the debrief questions to elicit dialogue about empathic care of people with CP and/or complex communication needs and to address negative attitudes and stereotypes.

The facilitator is to address the following issues sequentially during the debrief.

- What were you thinking and feeling as you were watching the film?
- What do you imagine Helen might have been feeling and thinking as the situation unfolded, and why? What words did you use to capture your feelings?
- What do you think Emma, the nurse, might have been thinking while caring for Helen? What words did you use to capture your feelings?
- How might Emma's first impressions have influenced the building of a therapeutic relationship between her and Helen?
- What did Helen need in this situation?
- Is there anything the nurse could have done to make Helen feel more at ease in that situation and to portray person-centered care?
- What is the relationship between empathy, poor health outcomes and patient safety when caring for people with complex communication needs?
- How might healthcare professionals' and students' prior experiences, perspectives and attitudes influence the care they provide to people with CP and/or complex communication needs?
- Would you have any concerns about assessing and caring for a person who has complex communication needs? Why? [Prompts: past experiences, stereotypical views, lack of knowledge, confidence or experience].
- Would you have made any preparations before meeting Helen based on the information you received at handover? [Prompts: reviewing her notes to see if there is any relevant information; try to find out more about the care of a person with CP including the use of alternative and augmentative communication strategies].
- As a result of what you have learned from this experience, what actions will you take when caring for a person with CP and/or complex communication needs in the future?
- Based on your responses to the previous question, develop personal SMART (Specific, Measurable, Attainable, Realistic, Timely) learning goals for enhancing your knowledge and skills when caring for people with CP and/or complex communication needs.

Final message (from Helen and Emma)

This short film can be played following the debrief to reinforce the key messages from the esimulation:

https://bournemouth.cloud.panopto.eu/Panopto/Pages/Viewer.aspx?id=4f92fef0-f61b-4f4b-9460-a96500ac82b2

Following the Debrief

Thank students for participating and remind them of the immense impact they can each have on the care of people with Cerebral Palsy and complex communication needs.

RESEARCH & EVALUATION

Students who have agreed to participate in the research should be given the Comprehensive State Empathy Scale (CSES)¹ pre-test (Appendix A) prior to the pre-brief and the CSES post-test (Appendix B) immediately following the debrief.

COMPREHENSIVE STATE EMPATHY SCALE (CSES)

The CSES was designed to take into account Batson's (2009) eight dimensions of empathy:

- 1. imagining how the other person is feeling and thinking
- 2. imagining how one would think and feel in the other person's situation
- 3. understanding another person's emotional and cognitive state
- 4. matching the neural response of the other person
- 5. experiencing the same or similar feelings as the other person
- 6. projecting oneself into the other person's situation
- 7. feeling distress for the suffering of the other person
- 8. feeling for the person who is suffering.

A challenge in measuring empathy is that most of the currently available scales measure *trait* empathy (empathy as a psychological disposition) rather than *state* empathy (empathy at a point in time). Trait empathy scales are not appropriate for pre-test post-test studies conducted over a short time frame as they rely on self-report of previous experience and behaviours. In lieu of a feasible method to assess state empathic accuracy, the approach taken with the CSES was to develop items that measure state empathy by adapting items from validated trait empathy questionnaires.

Psychometric testing of the CSES revealed good internal consistency with a Cronbach's alpha (CA) of 0.96. Factor analysis identified six factors:

- 1. Empathic concern (items 1-6) α 0.87
- 2. Distress (items 7-12) α 0.93
- 3. Shared affect (items 13-16) α 0.86
- 4. Empathetic imagination (items 17-20) α 0.82
- 5. Helping motivation (items 21-24) α 0.84
- 6. Cognitive empathy (items 25-30) α 0.93.

Levett-Jones, T. et al. (2017). Measuring the impact of a point-of-view disability simulation on nursing students' empathy using the comprehensive state empathy scale. *Nurse Education Today*. 59, 75-81. https://doi.org/10.1016/j.nedt.2017.09.007

Measuring empathy using the CSES

The CSES scenarios included in this toolkit relate to the measurement of empathy towards a person with cerebral palsy and complex communication needs. To ensure authenticity they were derived from a search of the literature to identify the difficulties encountered by people with CP wo require healthcare. The scenarios depict a young woman experiencing distress while in hospital. Each scenario also includes a relevant image. Each scale takes approximately 10 minutes to complete.

Participants are asked to respond to the questions on the CSES based upon their attitudes and feelings toward the person (Megan or Amy) described in the scenario pre and post exposure to the e-simulation.

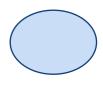
Each item is scored using a five-point Likert scale with response ranges from 1 (completely untrue) to 5 (completely true). Overall empathy scores are obtained by calculating the sum of the individual items of the CSES and subscales. Changes between pre and post empathy scores can be analysed using paired sample t-tests or nonparametric alternatives such as paired Wilcoxin Signed Rank Tests.

Researchers may also collect demographic information (such as age, gender, place of birth, previous experience working in aged care etc) and conduct correlations with CSES results.

REFERENCES

- Batson, C. These things called empathy: Eight related but distinct phenomena. (2009). In *The social neuroscience of empathy. Social neuroscience*. (Daniel J & Ickes, W eds.). Cambridge, MA: MIT Press
- Brunero, S., Lamont, S. & Coates, M. (2010). A review of empathy education in nursing. *Nursing Inquiry*, 17, 65-74.
- Charon, R. (2006). Narrative Medicine. Columbia: New York.
- Everson, N. Levett-Jones, T., Lapkin, S., Pitt, V., Vander riet, P., Rossiter, R. Courtney-Pratt, H., Gilligan, C., & Jones, D. (2015). Measuring the impact of a 3D simulation experience on nursing students' cultural empathy using a modified version of the Kiersma-Chen Empathy Scale. *Journal of Clinical Nursing*, 24, 2849-2858.
- Fields, S., Mahan, P., Tillman, P., Harris, J., Maxwell, K. & Hojat, M. (2011). Measuring empathy in healthcare profession students using the Jefferson Scale of Physician Empathy: Health provider student version. *Journal of Interprofessional Care*, 25, 287–293.
- Garcia, P., & Rossiter, M. (2010). Digital Storytelling as Narrative Pedagogy. In Gibson, D., & Dodge, B. (Eds.), *Proceedings of SITE 2010-Society for Information Technology & Teacher Education International Conference* (pp. 1091-1097). San Diego, CA, USA.
- Hatfield, E., Rapson, R. & Le, Y. (2011). Primitive emotional contagion: Recent research. In J. Decety and W. Ickes (Eds.) *The social neuroscience of empathy*. Boston, MA: MIT Press.
- Hemsley, B., Georgiou, A., Hill, S., Rollo, M., Steel, J. & Balandin, S. (2016). An integrative review of patient safety in studies on the care and safety of patients with communication disabilities in hospital. *Patient Education and Counseling*, 99, 501-511.
- Kelm, Z., Womer, J., Walter, J. & Feudtner, C. (2014). Interventions to cultivate physician empathy: a systematic review. *BMC Medical Education*, 14, 219.
- Levett-Jones, T. et al. (2017). Measuring the impact of a point-of-view disability simulation on nursing students' empathy using the comprehensive state empathy scale. *Nurse Education Today.* 59, 75-81.
- Petrucci, C., La Cerra, C., Aloisio, F., Montanari, P. & Lancia, L. (2016). Empathy in health professional students: A comparative cross-sectional study. *Nurse Education Today*, 41, 1-5.
- Ward, J., Cody, J., Schaal, M. & Hojat, M. (2012). The empathy enigma: an empirical study of decline in empathy among undergraduate nursing students. *Journal of Professional Nursing*, 28, 34-40.
- Williams, J. & Stickley, T. (2010). Empathy and nurse education. *Nurse Education Today*, 30, 752-755.
- Zeighami, R., Rafiie, F.& Parvizi, S.(2012). Concept analysis of empathy in nursing. Journal of Qualitative Research in Health Science, 1 (1), 27-33.

APPENDICES



Participant Code

APPENDIX A: CSES PRE-TEST

Please read and reflect on the story below then answer the questions on the following pages.

Note: Megan's story is based on a true account, but details have been changed ensure anonymity.



Megan is a 29-year-old woman with cerebral palsy. She requires a wheelchair to mobilise and her speech is slow and slurred. However, she describes her life as fulfilling and happy.

Over the last six months Megan had been finding it increasingly difficult to clear her throat so she was advised to limit her diet to thickened fluids. However, her swallowing ability continued to deteriorate, eventually resulting in aspiration pneumonia.

Megan was admitted to hospital to receive intravenous antibiotics. During this time a series of assessments were conducted, and it was identified that she was no longer able to clear fluids and protect her airway due to her impaired swallow and weak cough. Her doctor and speech pathologist decided that the best option would be for Megan to have a PEG tube inserted.

Megan underwent the surgical insertion of the PEG tube yesterday. Fiona, the registered nurse caring for her today came into her room at 11.30am and said, 'Well sweety, it's been a busy day but now I'm here now and I'm going to give you a bed bath and change you into a lovely clean hospital gown'. As Fiona began to remove her gown, Megan became agitated. She wouldn't allow Fiona to undress her and kept calling out 'leave me ... just leave me'. Eventually, Fiona became frustrated and left the room saying, 'I'll come back when you've settled down'. When Megan's sister arrived an hour later, she found Megan partially undressed, crying and feeling frustrated. Megan said to her, 'Why won't people ask me what I want. I don't want a PEG tube! And I don't want to stay in bed until lunch time or have a bed bath or wear hospital gowns. I have CP but I'm still a person and I should have a say in what happens to me'.

On the next pages, you will find a series of statements and questions. Please read and respond to each one, even if it seems very similar to another. Answer each question quickly, without spending too much time on any particular one.

Below is a list of feelings. On a scale of 1-5 please rate the extent to which you experienced each of these feelings in response to Megan's story.

- 1 indicates that you experienced this feeling *not at all*
- 5 indicates that you experienced this feeling *very much*

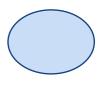
		Not at all				Very much
1.	Compassionate	1	2	3	4	5
2.	Moved	1	2	3	4	5
			1	1	1	, ,
3.	Soft-hearted	1	2	3	4	5
	0 11 11			Ι ο	T .	1 -
4.	Sympathetic	1	2	3	4	5
E	Tondor	1	1 2	l a	1 4	E
5.	Tender	1	2	3	4	5
6.	Warm	1	2	3	4	5
<u> </u>	Walli	•		0	1 '	
7.	Distressed	1	2	3	4	5
			•	•	•	
8.	Disturbed	1	2	3	4	5
						·
9.	Grieved	1	2	3	4	5
			1	1	1	
10.	Troubled	1	2	3	4	5
	Heart	4		I 0	1 4	I = 1
11.	Upset	1	2	3	4	5
12.	Afraid	1	2	3	4	5
12.	Allalu	Į į		١٥	4	J

Below is a list of statements. On a scale of 1-5 please rate the extent to which each statement is true for you in relation to Megan's story.

- 1 indicates that this is *completely untrue for you*
- 5 indicates that this is *completely true for you*

	Completely untrue			Comp	Completely true	
13. I found that the scenario affected my mood	1	2	3	4	5	
14. I was very affected by the emotions in this story	1	2	3	4	5	
15. I actually felt Megan's distress	1	2	3	4	5	
16. I experienced Megan's feelings as if they were my own	1	2	3	4	5	
17. I found myself imagining how I would feel in Megan's situation	1	2	3	4	5	
18. I found myself imagining myself in Megan's shoes	1	2	3	4	5	
19. I found myself trying to imagine how things looked to Megan	1	2	3	4	5	
20. I found myself trying to imagine what Megan was experiencing	1	2	3	4	5	
21. I would really focus on Megan's emotions if I was caring for her	1	2	3	4	5	
22. I experienced a strong urge to help Megan	1	2	3	4	5	
23. I would get really involved in trying to help Megan	1	2	3	4	5	
24. I found myself thinking about what could be done to help Megan	1	2	3	4	5	
25. I feel confident that I could accurately describe Megan's experience from her point of view	1	2	3	4	5	
26. I found it easy to understand Megan's reactions	1	2	3	4	5	
27. I found it easy to see how the situation looked from Megan's point of view	1	2	3	4	5	
28. Even though Megan's life experiences are different to mine, I can really see things from her perspective	1	2	3	4	5	
29. I am sure that I know how Megan was feeling	1	2	3	4	5	
30. I feel confident that I could accurately describe how Megan felt	1	2	3	4	5	

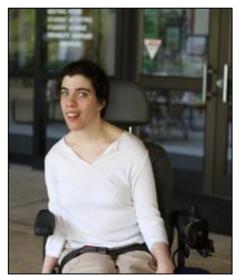
APPENDIX B: CSES POST-TEST



Participant Code

Please read and reflect on the story below then answer the questions on the following pages.

Note: Amy's story is based on a true account, but details have been changed ensure anonymity.



Amy James is a 32-year-old woman with cerebral palsy (CP). She has very limited mobility and needs to use a wheelchair. Although Amy has complex communication needs she is able to use a range of different augmented and alternative communication strategies effectively, and she has a full and happy life, supported by her family and close friends.

Over the last six months Amy had been experiencing intermittent episodes of abdominal pain. Although it had been getting much worse, she had not told anyone about it as she was scared that she might have to go to hospital. Amy's previous experiences of hospitalisation had been frightening and distressing. Eventually, her mother found her crying with pain and called an ambulance.

Amy was admitted to hospital for investigation of her abdominal pain. The nurses responsible for Amy had limited

experience caring for people with CP. That, coupled with the fact that she is in a busy acute care ward, mean that Amy's care needs have sometimes been overlooked. She has not been out of bed for two days and this morning, she was unable to make her nurse understand that she needed to go to the bathroom. The nurse had eventually become frustrated at not being able to understand what Amy was trying to say and left the room saying that she would find someone who could work out what 'the problem is'. Before she left she tied the call bell on the bed rail and told Amy to press it if she needed anything. But because Amy has limited dexterity in her hands she was unable to use it. By the time her mother came to the hospital two hours later Amy had wet the bed; and she was distressed, humiliated and shivering with cold. Her pain was much worse, and she kept saying to her mother 'take home'.

On the next pages, you will find a series of statements and questions. Please read and respond to each one, even if it seems very similar to another. Answer each question quickly, without spending too much time on any particular one.

Below is a list of feelings. On a scale of 1-5 please rate the extent to which you experienced each of these feelings in response to Amy's story.

- 1 indicates that you experienced this feeling *not at all*
- 5 indicates that you experienced this feeling *very much*

		Not at all				Very much
1.	Compassionate	1	2	3	4	5
						·
2.	Moved	1	2	3	4	5
			T -	1 -	T .	1
3.	Soft-hearted	1	2	3	4	5
	Cumpathatia	1	1 2	1 2	1 4	<u>-</u>
4.	Sympathetic		2	3	4	5
5.	Tender	1	2	3	4	5
<u> </u>	Tondor	•	1 -			
6.	Warm	1	2	3	4	5
7.	Distressed	1	2	3	4	5
	8:		T 0	T 0	1 4	T = 1
8.	Disturbed	1	2	3	4	5
9.	Grieved	1	2	3	4	5
<u>J.</u>	Olleved	1		1 3	¬	5
10.	Troubled	1	2	3	4	5
11.	Upset	1	2	3	4	5
	·					
12.	Afraid	1	2	3	4	5

Below is a list of statements. On a scale of 1-5 please rate the extent to which each statement is true for you in relation to Amy's story.

- 1 indicates that this is *completely untrue for you*
- 5 indicates that this is *completely true for you*

	Completely untrue			Comp	Completely true	
13. I found that the scenario affected my mood	1	2	3	4	5	
14. I was very affected by the emotions in this story	1	2	3	4	5	
15. I actually felt Amy's distress	1	2	3	4	5	
16. I experienced Amy's feelings as if they were my own	1	2	3	4	5	
17. I found myself imagining how I would feel in Amy's situation	1	2	3	4	5	
18. I found myself imagining myself in Amy's shoes	1	2	3	4	5	
19. I found myself trying to imagine how things looked to Amy	1	2	3	4	5	
20. I found myself trying to imagine what Amy was experiencing	1	2	3	4	5	
21. I would really focus on Amy's emotions if I was caring for her	1	2	3	4	5	
22. I experienced a strong urge to help Amy	1	2	3	4	5	
23. I would get really involved in trying to help Amy	1	2	3	4	5	
24. I found myself thinking about what could be done to help Amy	1	2	3	4	5	
25. I feel confident that I could accurately describe Amy's experience from her point of view	1	2	3	4	5	
26. I found it easy to understand Amy's reactions	1	2	3	4	5	
27. I found it easy to see how the situation looked from Amy's point of view	1	2	3	4	5	
28. Even though Amy's life experiences are different to mine, I can really see things from her perspective	1	2	3	4	5	
29. I am sure that I know how Amy was feeling	1	2	3	4	5	
30. I feel confident that I could accurately describe how Amy felt	1	2	3	4	5	

Do you have any comments to make about the e-simulation experience?

APPENDIX C: EPILOGUE

Educators can use the 'back stories' provided below either following the debrief (if there is enough time) or as a stimulus for classroom discussion and/or assessment items. Both of the back stories are designed to help learners better understand the experiences and perspectives of Helen and Emma (her nurse).

Helen's Story²

Helen was 42-years-old when she was taken to hospital following a fall at home. She had sustained a deep laceration to her right leg which required surgery. Helen lived in her own home the south of England with 24-hour care and support from personal assistants (carers). She had cerebral palsy (CP), a lifelong condition and neurological disorder affecting body movement, muscle control, muscle co-ordination, muscle tone, reflex, posture and balance. For Helen, this meant she had very limited mobility, needed to use a wheelchair and required the support of two people and a hoist to transfer to bed. Although Helen also had complex communication needs she had developed a range of different strategies to help her to communicate with other people.

When Helen arrived on the ward, she was feeling anxious and concerned. Prior hospital admissions had been very variable, some were good, a few were excellent, but many had been frightening and distressing and left a long-term impact on her. On this occasion, Helen's first meeting with Emma, the nurse assigned to her, had left her feeling frustrated, vulnerable and anxious. This was because Emma had struggled to communicate with her and, because of this Helen's admission assessment had not been accurately or fully completed. Helen was aware that some vital information about her, and her current needs was missing, and that his had the potential to compromise her safety while in hospital.

Soon after meeting Emma, Helen had begun to feel frustrated by her reactions as they, as they indicated that, as her nurse, she was making inaccurate assumptions about her. For example, Emma's communication and interpersonal skills suggested that she had assumed Helen had a learning disability and/or hearing loss, in addition to her observable physical disabilities. Emma's reactions also suggested that she knew little about CP and how this affects people, and had limited awareness of the broad range of alternative or augmentative communication strategies and tools available to help healthcare workers communicate with patients who have complex communication needs.

Nurse Emma's approach and attitude left Helen feeling isolated, patronised, humiliated and frustrated as well as concerned for her own safety. Helen was not sure if the nurse had understood her when she tried to explain how she had injured herself, that she was in pain, had a PEG (Percutaneous Endoscopic Gastrostomy) tube, or if she was aware of the implications of these factors in terms of providing safe care. Helen's anxiety and concern had been further deepened when the nurse told her that she was making her day 'very difficult' and had walked away leaving Helen with no means of calling for help should she needed to.

Emma's Story

Emma had recently qualified as a registered nurse. When arriving for a morning shift soon after starting on her new ward, Emma was told she would be looking after Helen, a 42-year-old woman with cerebral palsy (CP) and who had complex communication needs and used a wheelchair. Emma had been told during handover that Helen was being admitted with an injury to her leg that required surgical treatment, and that her hospital admission assessment needed to be completed.

Emma had never met or cared for anyone with CP before, nor had she studied the condition while at university; so, she didn't know anything about how CP affects people. She had also never cared

² Sadly, Helen passed away in 2018 after a short illness just as this film project was nearing completion.

for someone with complex communication needs. Consequently, she felt totally unprepared for meeting Helen, and was concerned that she might not have the necessary knowledge, experience or skills to build a rapport with Helen, complete her assessment and accurately identify her needs for treatment and care. As a newcomer to the team she didn't feel able to ask for guidance or support as she feared being judged as incompetent or stupid by other staff members. So, she concealed her concerns, accepted the responsibility she had been given, and went to meet her patient.

When Emma met Helen, her fears about not having appropriate knowledge, experience and skills to care for her safely and effectively were soon realised. Emma felt totally unprepared for carrying out an assessment of someone who had a communication disability. She soon felt incompetent, frustrated by her limitations, and almost completely overwhelmed by her lack of ability to communicate with and understand Helen. She didn't want let Helen down or cause her concern, but believed that her inability to communicate had the potential to trigger feelings of frustration, concern and worry in her patient. Although Emma had tried to communicate with Helen using the admission assessment form to guide her, she couldn't understand most of Helen's replies and the assessment remained incomplete. Emma felt it would be rude to tell Helen that she didn't understand her, or to keep asking her to repeat what she had already said. She felt at a loss to know what to do other than to walk away. She wanted a few moments to collect her thoughts while she tried to find a way of overcoming the challenges she currently faced without alerting her colleagues to her incompetence.

APPENDIX D: SUPPLEMENTARY TEACHING AND LEARNING RESOURCES

The films³ profiled in the links below each depict different aspects of Helen's experiences of hospitalisation. They were designed to enhance empathy and raise awareness of the challenges that can be experienced by people with CP and complex communication needs when interacting with healthcare professionals.

Educators can use the films in various ways, for example as part of an e-simulation or as a stimulus for classroom discussion and/or assessment items.

The complete set of films, including introduction and final messages:

https://bournemouth.cloud.panopto.eu/Panopto/Pages/Viewer.aspx?id=9c1aa5b7-549d-4bcc-93d7-a96500acb7ca

Individual films with pre- and debrief activities included:

Introduction

https://bournemouth.cloud.panopto.eu/Panopto/Pages/Viewer.aspx?id=4e95cd15-feb0-40e6-89c4-a96500ac9069

[Note: Film 1 is included on page 5 as part of the e-simulation]

Film 2 - Nurse-Patient Communication

https://bournemouth.cloud.panopto.eu/Panopto/Pages/Viewer.aspx?id=bc20b910-cf99-4444-9f76-a96500ac6da8

Film 3: I am here!

https://bournemouth.cloud.panopto.eu/Panopto/Pages/Viewer.aspx?id=5e05108d-ddd1-4f3f-b979-a96500ac6d87

Film 4: I'm sorry Helen I don't understand...

https://bournemouth.cloud.panopto.eu/Panopto/Pages/Viewer.aspx?id=7482dd52-ded9-41fb-899d-a96500ac6d6a

Film 5: Acknowledging the person

 $\underline{https://bournemouth.cloud.panopto.eu/Panopto/Pages/Viewer.aspx?id=1f4078dd-20be-46e6-b4db-a96500ac6d52}$

Film 6: Finding Alternative Ways

https://bournemouth.cloud.panopto.eu/Panopto/Pages/Viewer.aspx?id=55edc654-3557-4cde-9106-a96500acd885

Final messages

https://bournemouth.cloud.panopto.eu/Panopto/Pages/Viewer.aspx?id=4f92fef0-f61b-4f4b-9460-a96500ac82b2

³ We are very grateful to be able to include these films in the Virtual Empathy Museum; and we ask that you acknowledge Helen Ross, Sue Baron and the project team when you use them in your teaching (see page 4 for citation details).