

**Association for Paediatric**

**Palliative**

**Medicine**

**TOP TIPS**

**FOR DOCTORAL STUDENTS RESEARCHING ISSUES RELATED TO**

**PALLIATIVE CARE FOR CHILDREN AND YOUNG PEOPLE**

Much of what we do in children’s palliative care currently is eminence-based, rather than evidence-based[[1]](#footnote-1). Whilst sharing experience and wisdom is valuable it is also important to ensure that the evidence base is strong so that children, young people and their families receive the highest standard of care. This requires the fostering of a research culture in the specialty to support the development of researchers who pursue rigorous enquiry and generate robust evidence. This paper is written for those who may be contemplating or undertaking a PhD in a subject related to children’s palliative care.

The challenges and opportunities posed by studying for a PhD vary with the individual’s starting point. They may be a clinical professional working with children and young people (CYP) with palliative care needs who has not undertaken academic work for a considerable length of time and who is unfamiliar with working with children and families in a research context; a professional working in allied fields with limited experience of working with CYP and their families in these circumstances; or a student or academic familiar with academic approaches and up-to-date methodologies but with little experience of clinical issues. This paper, based on the experiences of those who have gone before, offers nuggets of insight, advice and encouragement for those starting down this path.

**Starting a PhD:**

**→ General Advice for those considering a PhD in Children and Young People’s Palliative Care**

1. Finding a topic: take time, read, speak to leaders in the field (academic and clinical) and think about the areas that interest you; but also be open-minded to new areas or aspects. Listen to all the good advice offered in making your final decision on the actual topic of your research. It needs to be worthy of a PhD but not too big to be unachievable in the time available.
2. Consider further studies such as a Master’s or an MRES in a related field first to get a good feel for the subject area and to develop and/or update your research skills. These studies can be challenging in their own right, but very worthwhile.
3. Conducting research in children’s palliative care may bring some specific challenges, but the specialty has aspects in common with other areas: for example, children with complex or long-term conditions and adult palliative care. Depending on the topic, there may be overlap with various academic areas such as adult and paediatric medicine, nursing, psychology and social care. This means that there will be helpful contributions to the evidence base from a range of different backgrounds.
4. Consider that it is possible to undertake your PhD at a university that does not have a track record specifically in children’s palliative care. There are other factors to consider such as their expertise in particular research methods.
5. Entry requirements: usually a good degree to demonstrate academic rigour (often 2:1 or equivalent), a willingness to learn, curiosity, commitment, perseverance and resourcefulness.
6. Funding: If you are looking for help with the cost of a PhD you may be able to get a studentship or scholarship, or even a PhD loan, particularly for part time students. Funding postgraduate research may ne challenging. You can find more information at <https://www.findaphd.com/funding/guides/phd-funding-guide.aspx>
7. There are various ways of doing a PhD – part time or full time. Choose what’s best for your personal circumstances, timetable and finances.
8. Cherish the opportunity. You may dedicate several years of your life to this, so make sure that you are doing something you enjoy (mostly) and consider important.
9. Involve families when constructing your question or deciding upon the specifics.

**→ Starting a PhD: for those who are primarily clinicians rather than academics**

1. Returning to study is a role change. Be humble, listen and learn.
2. You have entered a new environment - be patient, broaden your horizons, and relish it.

**→ Starting a PhD: for those without prior experience in CYP palliative care**

1. It can be challenging to work with children, young people and families who are living with life-limiting illness. Exploring the impact of life-limiting illness and grief in depth can take its toll on you as a researcher, so it is important to understand the boundaries around your role, use the support mechanisms in place and build in regular time for reflection and other activities.
2. Children, parents and family members rapidly become expert in the care and support that is relevant to them, often living with very rare conditions/syndromes/treatments and challenging life-styles. Respect their knowledge, their time, and value the privileged access you gain as a researcher.
3. Living with serious illness, unpredictable health needs, or uncertainty about the future, can be exhausting. Adding research participation to the list of daily activities may be too difficult. As a researcher, be flexible and accommodating and don’t take it personally if people decline to participate in your work.
4. Think carefully about how you will communicate with children, young people and families in your research and be sensitive about the terminology that you use. It can help to read widely on the topic so that you have a good understanding of the children’s palliative care context. You are likely to need to find acceptable ways to talk about death and dying with a range of family members, with a variety of different backgrounds and cultures. This might be with children who have severe cognitive impairment or with parent carers who may have learning difficulties themselves. It is important to recognise that there are a wide range of different life-limiting or life-threatening conditions which follow very different trajectories and it is common for children to have fluctuating health, with rapid deteriorations and sometimes to die very suddenly. It will be important to think about these issues when you are choosing the cohort that you will work with.

**The Voice of Experience:**

“In England and Wales there is now an NIHR academic career path, so not all clinicians will be making such a big change in their work to undertake research. For some, this may be part of their career from the start.

Your choice of supervisor(s) is really important. You will benefit from doing your research alongside a team with relevant interests. Sometimes you can have a lead supervisor from the university where you are registered and additional supervisors from other institutions. There can be drawbacks to having too many supervisors if there are disagreements.

My three supervisors had backgrounds in children’s nursing, public health and social policy/public engagement, which brought a variety of rich and diverse insights. They relied on me to bring the children’s palliative care background to the table.”

**→ Early stage of a PhD: knowing the field, planning your project, gaining ethical approval**

1. Think carefully, then think again, about your research question. There is a wide spectrum of conditions with different illness trajectories, so you may need to narrow down your research to a particular condition, or groups of condition or you may want to consider an issue that transcends conditions.
2. Read lots – not just about your subject, but sometimes go off on a tangent too. This is a time to explore, and being a student gives you the privilege of doing that.
3. Have a flexible, bite-sized plan. Don’t be overwhelmed by the scale of a PhD, focus instead on small steps along the way.
4. Accept that the direction of your work may meander over time. It is not linear from start to finish.
5. Get organised - find reference management software you like early on and stick with it. Check licensing arrangements for software to ensure compatibility and permissions where you will be working.
6. Academic writing is a skill that needs regular practice – start early, write often, and get a routine for putting your thoughts clearly onto paper. You can always edit later.
7. Be clear with your supervisor about roles, responsibilities, and expectations from an early stage. Treasure their feedback – and if you disagree, have healthy respectful debate. They want to see you succeed.
8. A PhD can be a very isolating experience, so make sure you meet other students and colleagues. No-one else is doing your project, but you can still learn a lot from each other, and share the challenges. ‘*eCPC PhD News*’ is a closed Facebook group specifically for PhD students undertaking research in children’s palliative care.
9. Make the most of the generic training opportunities that your university offers – both online and face-to-face. This may cover a range of topics, from time management to training to teach, trans-disciplinarity to research governance, epistemology & ontology – all fundamental building blocks for your future in the research world.
10. Look after yourself – book breaks, keep fit, keep connected with a supportive network and have fun – regularly!
11. Ethics approval is a necessary step for any project involving contact with children, young people and their families.
12. NHS ethics processes are detailed, multi-step, and usually take many months before approval is granted
13. Recruitment from non-NHS sites will still require approval from your university and also possibly the relevant NHS ethics committee.
14. Hospices and other organisations you are working with may also have their own ethics procedures. Allow plenty of time for this in your project timeline.
15. Think about general ethical and legal issues around respect, anonymity and confidentiality; informed consent and voluntary participation. You should also consider:

* storage and access to materials.
  + What is your plan if potentially harmful information is revealed?
  + Balance potential benefits and harms to all individuals involved in a study – this includes the children and young people and family members taking part, AND staff who may be affected – including you, the researcher.

1. Many PhD programmes have interim assessment processes. View these as learning opportunities: understand both the broader and directly relevant literature, be clear about your questions and methodology and the philosophical underpinnings and don’t waffle.

**→ Mid-stage PhD: Undertaking fieldwork: Planning, Recruitment, and Data Collection**

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1. Recognise potential gatekeeping issues – management staff for organisations, clinicians for patients, parents for their children. Try to understand why they feel protective and have a strategy to communicate with them, with appropriate information about the study and opportunities to respond to any questions or issues from their perspectives. Whatever methods you use, don’t be disappointed if your response rate is low in comparison to all the effort that you put into recruitment. No matter how on-board health care professionals are with your study, they will gate-keep.
2. Have robust practice a round information governance, in particular ensure there are appropriate guarantees of anonymity and confidentiality in place for any participants who have concerns that their details will be passed on to national or security agencies (e.g. refugees, immigrants).
3. Be aware of the best way to communicate with participants and whether you will need to use assistive communication methods.
4. For those whose first language is not English, translation services may be required. Consider whether it is appropriate to involve someone known to their community to assist with communication? Consider the pros and cons of this and make appropriate arrangements.
5. Think about the level or threshold of anonymity and maintaining protection of the family’s identity; balancing this with the degree of richness/ blandness of content that you record.
6. Conducting the research may be distressing for the participants (and you) - plan for how to manage this for them and you; try to end on a positive note. It may be appropriate to offer participants emotional support, such as the Together for Short Lives Helpline.
7. Think about lone working issues and ensure that you adhere to university policies and have strategies in place to ensure that you are safe.
8. You will need to check out the data security of systems such as Skype and Facetime for recording interviews as these are not covered by data protection laws. Consider alternative modes of communication/data collection where possible in order to comply with relevant legislation.
9. Computer data storage will need to be considered. Remember that you cannot transfer material outside the European Economic Area (i.e. to the US). You should check where your data server is situated. Further information can be found at <https://ico.org.uk/for-organisations/guide-to-data-protection/>
10. Recruitment of participants takes time - don’t feel defeated during lulls.
11. You will need to curate your data carefully at all stages – whether you are transcribing, translating, anonymising, storing or analysing it.

**The Voice of Experience:**

“Something that did surprise me and I hadn't fully appreciated, even though it is in the literature, was the tension between being a clinician and a researcher and the empathy I developed with key informants. There is a useful paper related to this by Brunero, Jeon and Foster (2015) 'The journey of positioning self as both mental health nurse and qualitative researcher' which I found useful.

Check your recording device is working properly before you start interviews and make sure you have spare batteries, write up field notes straight away and allow loads of time for transcription as it takes ages.

Focus groups – if parents bring babies or toddlers along, you may be prising the Dictaphone out of little hands, or have babies sitting on your lap.

Be flexible - allow for the sessions to take different directions in response to the participants – I got some of my most valuable material this way

When I was doing my PhD I was travelling late at night (evenings were best for families) and so I had to think about safe lone working. I adhered to the university’s lone working policy but also had a strategy in place so that my primary supervisor knew where I was going. I would text her when I was home safely."

**→ Late-stage PhD: Writing up**

1. Create a timeline and review it regularly with your supervisor(s). Set achievable goals for writing, correcting and polishing chapters and be aware that final formatting takes a long time.
2. Identify times for writing that work best for you.
3. Discuss examiners early with your supervisor(s)and avoid internal and external conflicts.
4. Set up a pre-formatted template for your thesis and populate it with headings, then text. Don’t leave all the formatting to the end.
5. Reference consistently and adhere to University requirements.
6. Save systematically and daily. Back up in the cloud and/or on an external hard drive or data stick, being cognisant of GDPR.

**The Voice of Experience:**

“I backed up every evening on my University system, One Drive, another PC and a hard drive. It takes about ten minutes maximum but in times of data theft, data threats and electrical storms, worth the ‘strict’ daily saving routines. It also means that if you’re travelling to conferences, or your laptop gets stolen, your data is retrievable and safe, if password protected, somewhere in the cloud, anywhere in the world.

Go for a walk with a recording device on your phone. Some of my best ideas have emerged whilst walking for a couple of hours on the ’South Downs Way’.

The Pomodoro technique helped me - try writing for 40 minutes, take a five-minute break, (feed the cat, make a drink), then straight back to the PC. Continue to do this routine throughout the morning. Take a couple of hours to exercise/have a light lunch and carry on working this way for the rest of the day, depending on your body clock and other commitments.

PhD Boot Camps can help you to write, think and structure in a formal, silent environment with other students. I found this helpful when I had a short but worrying period of ‘writers block’.

I arranged writer`s retreats – four days maximum – just by the seaside with lots of walking.”

**→ The Viva:**

1. You may wait several months between submitting your final thesis and attending your viva examination.
2. Depending on your other work responsibilities and the timescale, use the time profitably; possibly to complete a final report for your University’s Human Research Ethics Committee (HREC), NHS RECS or other RECS as well as a short report on the findings for participants, written in plain English.
3. Allow at least a month for preparation in order to reread your thesis several times before the scheduled viva. (Examiners are usually given six weeks to read and examine your thesis). Carefully read your thesis, thinking about the ideas and findings and issues for further work. Also check for typos, formatting and grammatical errors. Make a table of these and print copies to take to the viva for the examiners and Chair, *should* they draw these to your attention during the viva. Don’t proactively offer the table of corrections to them.
4. Check your thesis for clarity, potential contradictions, repetition.
5. You might want to consider setting up a mock viva.
6. Practice answering the questions that you KNOW will come up.
7. Bring your own marked copy of your thesis to your viva. You can refer to your thesis and notes where you would like to check information.
8. A supervisor may or may not accompany you to the viva, depending on the University. If they do they sit in the background and take notes. They cannot ask any questions.
9. Think and take time before answering questions. Seek clarification if uncertain about the questions being asked.
10. Your Viva will last about one and a half hours. You will then be asked to leave the room for about half an hour.
11. You will be recalled to the room and advised of the outcome of your Viva. Most students will have some corrections to be completed within an agreed period of time and these will be confirmed in writing by the Research School, usually within a few weeks of the Viva.
12. Complete any corrections advised by your examiners and do not add any additional material.
13. You will subsequently be invited to a degree awards ceremony, which could be up to a year later.

**The Voice of Experience:**

“The Chair literally chairs the proceedings and ensures that the viva formalities are adhered to.

Don’t refer to yourself as ‘Dr’ until you receive your official certificate/ notification from the University!”

**→ Publication and Dissemination:**

1. You may have already published on the journey towards your doctorate, but if not it’s good to start working on papers as soon as you have completed your thesis. Your work should be of interest to peer reviewed journals, especially where your thesis has highlighted valuable empirical findings and raised useful methodological and theoretical arguments.
2. Look for opportunities to share and disseminate your research at national and international conferences
3. For many, securing post-doctoral work is an imperative as quickly as possible. Keep your CV, personal profile and publication list up to date.

**The Voice of Experience:**

“The period following submission, viva, corrections and then moving on is a tricky ‘liminal’ space and can be something of an anti-climax (although if you have a family they will be pleased to have you back!) I’ve been lucky, one of my supervisors is keeping my brain and research input very much alive, so I don’t lose momentum and connection with my specialist area.”

**And finally:**

Completing your PhD is not the end of the story, but hopefully your first step towards contributing to the evidence base relating to children and young people with life-limiting or life-threatening conditions and their families and to enhancing a growing research culture across the children’s palliative care sector.

Please let us know of your own reflections/top tips in order to help researchers of the future.

Why not consider joining our national community of doctoral students in this field to share ideas and provide mutual support. **You can contact** [**lizzie.chambers@togetherforshortlives.org.uk**](mailto:lizzie.chambers@togetherforshortlives.org.uk) **to find out more.**

***These Top Tips were developed by the members of the Together for Short Lives (TfSL) and Association of Paediatric Palliative Medicine (APPM) Doctoral Students Taskforce. This is a sub group of the TfSL/APPM Joint Research Group, which is chaired by Professor Myra Bluebond-Langner.***

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1. Guide to Children’s Palliative Care, 4th edition. Together for Short Lives, 2018. [↑](#footnote-ref-1)