

## **Taking for a Walk *A Dog with a Tail at both Ends***

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### **Abstract**

Performance drama provides the appropriate context for debates on the rights of those whom Society chooses to define as disabled – and therefore potentially subject to future curative treatment – to say “No!” As a children’s physician practising in paediatric disability and palliative care, I believe that the practice and study of the arts considerably enriches the medical practitioner, and ultimately makes our practice better for our patients and their families who we are endeavouring to serve. For me, the challenging journey of the playwright/paediatrician, leading to the performance of my play *A Dog with a Tail at both Ends*<sup>1</sup> serves this greater purpose. In the play, Jo, an adolescent girl with Down’s syndrome, is given an experimental treatment that reverses her cognitive impairment, but leaves her confused and isolated in a world she does not understand.

The arts clearly have the important role to integrate and be representative of the community they serve. However, this process is still not without its major difficulties, not the least of which are the considerable challenges of putting on a play in the first place. To date, the play has had five rehearsal/performance cycles including a performance by medical student actors at the Royal College of Paediatrics and Child Health Annual Meeting in 2010. However, in spite of strenuous efforts, I have not yet succeeded in having the play performed with Jo being played by an actor with Down’s syndrome.<sup>2</sup>

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<sup>1</sup> The full version of the play is available at [https://www.youtube.com/watch?v=PHU\\_EldWhb4](https://www.youtube.com/watch?v=PHU_EldWhb4)

<sup>2</sup> We were unsuccessful in 2009 with an application through Oxford Brookes University for Wellcome Trust funding. Over subsequent years, I formally submitted the play to the Royal

## Introduction

I am a full time NHS consultant community paediatrician working within the United Kingdom. I lead my Child Health Department in paediatric neurodisability and undertake some non-oncological palliative care. My play *A Dog with a Tail at both Ends* was inspired at the time of its writing, in 2006, by my daily clinical involvement in palliative end-of-life care with several children with complex neurodisability and one such patient in particular.<sup>3</sup>

I wrote the play firstly to improve both my understanding and ability to deliver care for children with complex neurodisability. I hope that the same applies particularly to all of the student actors and the audiences who have heard it. The play is downloadable from the journal website. I would be happy to discuss future performances and further development with anyone who is interested.

As the words “disabled” and “disability” come with such loaded meaning, I shall define my clinical practice further. My patients are children with both severe physical and cognitive impairment. Their combined difficulties are so profound that they are totally care-dependent for even the very basic needs and often it is extremely difficult, if not impossible, to determine their cognitive level. Communication is at the level of a smile, grimace, cry or subtle change in body tone. Even simple “switch” devices, allowing choices to be made, may sometimes not be successful. I should state from the outset that these children live full and meaningful lives. Some indeed, whose lives are measured few in years, can nevertheless live

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Court, National, Birmingham Repertory, Dergate and Soho theatres amongst many others as well as to different directors. I also contacted several disabled theatre companies and I offered this play unconditionally for them to take forward, but was told they only use their own writers. Mrs Veronica Broomhall, Artistic Director of New Creations Theatre Company, Wellingborough UK verbally agreed to take the play forward, but she sadly died in 2016.

<sup>3</sup> Andrew Williams, “Quintessence”, *Medical Humanities*, <<http://mh.bmj.com/content/early/2011/11/10/medhum-2011-010058.info>> [accessed 26 December 2017]; BBC Hospice Appeal Film for Children in Need 2012, accessible worldwide: [http://www.youtube.com/watch?v=y\\_w\\_ltd7UhQ](http://www.youtube.com/watch?v=y_w_ltd7UhQ) [accessed 6 December 2012]

many other children's lifetimes' worth of happy experiences. I welcome the 2001 WHO definition of disability, which takes into account the social aspects of disability and does not see disability only as a "medical" or "biological" dysfunction.<sup>4</sup> Within my practice, in the early twenty first century, there are currently no treatments which reverse paediatric neurodisability. The WHO definition recognises that, for example a child with a medical diagnosis of cerebral palsy, will remain with this diagnosis irrespective of how socially just a society becomes. However, I fear that the advocates of the social model choose to ignore the hard facts and may see them as just another form of "disability oppression"<sup>5</sup>: "Rather than adjust social environments to meet differing bodily needs, medical interventions seek to cure the individual 'abnormal' body. Disability activists resist these individualising and medicalizing approaches by reframing disability as a social restriction and oppression rather than simply a medical problem".<sup>6</sup> I hope by this paper to demonstrate that, at least from my perspective, this is not the case.

Seeing the issue as merely a matter of medical versus social model of disability is both unhelpful and extreme. Ultimately, disability, irrespective of the metaphor, is a lived reality for the child and his/her carers. Within the clinical context of my practice, I profoundly disagree with the medical model of disability that "locates impairment in the individual as someone who lacks the full complement of physical and cognitive elements of true personhood and who must be cured or rehabilitated".<sup>7</sup> I disagree that the medical model always sees the disabled person as having to be cured or rehabilitated. I disagree that the disabled child lacks the full complement of personhood. From a child health professional perspective (in the hope of bridging the

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<sup>4</sup> WHO *International Classification of Functioning, Disability and Health (ICF)* <<http://www.who.int/classifications/icf/en/>> [accessed 25 October 2012]

<sup>5</sup> Cf. James Charlton. "The Dimensions of Disability Oppression", in *The Disability Studies Reader*, ed. by L.J. Davis, (London: Routledge, 2006), pp. 217-231

<sup>6</sup> Bradley Lewis, "A Mad Fight: Psychiatry and Disability Activism", in *The Disability Studies Reader*, ed. L.J. Davis, (London: Routledge, 2010), pp. 339-355 (p.340)

<sup>7</sup> Michael Davidson, "Universal Design: The Work of Disability in an Age of Globalization", in *The Disability Studies Reader*, ed. L.J. Davis, (London: Routledge, 2006), pp. 117-131 (p.119)

medical and social model of disability), I feel obliged to mention how hard the Royal College of Paediatrics and Child Health is working, not only on the behalf of all the children in the UK, but also specifically in trying to help children with disabilities and their families against the significant social exclusion they still face. One such example is *Disability Matters*, led by the Royal College of Paediatrics and Child Health and launched in 2016. *Disability Matters* “is a free and flexible learning resource to help those who work, volunteer or engage with disabled children and young people (aged 0 to 25 years) and their families to support them as effectively as they can”.<sup>8</sup> *Disability Matters* seeks to address the barriers that make society disabling.

My clinical practice is at the other end of the spectrum. It is completely different from dealing with a deaf family and resolving the issues of medical care by health care professionals being fluent in makaton sign language.<sup>9</sup> In my practice, within this context, there is no cure or rehabilitation. It is a journey of acceptance, of “growing into difficulties”. Usually over many years, it involves working with the child, their family and many others to address these issues as they evolve and new ones arise. Very often in my practice there is no formal medical diagnosis, just a list of medical challenges to be faced and dealt with as best as you can.

I do my work because I find it personally deeply rewarding. Looking back, it seems that my patients have found me, rather than the other way round. For me, each of my patients has an equal and immeasurable worth. I tell my patients and their parents/carers that my job is to keep him/her “pink and perky”, pain free and out of hospital for as long as possible so that he/she can enjoy the best quality of life he/she can. Recent evidence suggests that care providers of disabled children have

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<sup>8</sup> *Disability Matters in Britain 2016: Enablers and Challenges to Inclusion for Disabled Children, Young People and Their Families*, (Royal College of Paediatrics and Child Health, 2016),

<[https://www.rcpch.ac.uk/system/files/protected/education/RCPCH%20DM%20iPDF%20Inclusion%20Report\\_2016\\_IF\\_R8.pdf](https://www.rcpch.ac.uk/system/files/protected/education/RCPCH%20DM%20iPDF%20Inclusion%20Report_2016_IF_R8.pdf)> [accessed 18 November 2017]

<sup>9</sup> Rebecca Garden, “Disability and Narrative: New Directions for Medicine and the Medical Humanities”, *Journal of Medical Ethics, Medical Humanities*; Vol. 36, Issue 2 (2010), <<http://mh.bmj.com/content/36/2/70>> [accessed 26 December 2017], (pp. 70-74)

a good quality of life.<sup>10</sup> Indeed, disabled children see their quality of life as no different from other children.<sup>11</sup> For me whether a child can give and receive love is the bottom line. This love can be expressed by a smile or even a change of muscle tone. For the parent or carer, the receipt of such love is worth the world.

Given the complexities of these children (whose neurology, especially with neurodegenerative conditions, is often rapidly evolving), to help them live as full a life as possible is very often a considerable challenge for the child and his/her families. Some interventions are physically invasive such as gastrostomy feeding which has become commonplace in UK practice over the last twenty years. Indeed gastrostomy feeding is now used in over one quarter of the children I manage at my local Special School.<sup>12</sup> The care also involves the successful and timely administration of many medications – often more than ten, each mostly two to four times a day as well as the requirement of specialist home adaptations including a wet room and hoist. Lastly, one cannot ignore the considerable suffering these children may sometimes face. This is not only as a consequence of, for example, major orthopaedic surgery necessary to maintain a good quality of life. The conditions themselves, for reasons still unclear, may generate intense continuous pain. In the latter case, these children, and especially those with progressive neurodegenerative disorders, may ultimately require long-term combined subcutaneous infusions of controlled medications such as morphine and ketamine.

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<sup>10</sup> John R. Bach, J. Vega, J. Majors, A. Friedman, “Spinal Muscular Atrophy Type 1 Quality of Life”, *American Journal of Physical Medicine and Rehabilitation*, Vol. 82, Issue 2 (Feb 2003), <<https://www.ncbi.nlm.nih.gov/pubmed/12544760>> [accessed 26 December 2017], (pp. 137–142)

<sup>11</sup> Heather O. Dickinson, K.N. Parkinson, U. Ravens-Sieberer, G. Schirripa, U. Thyen, C. Arnaud, E. Beckung, J. Fauconnier, V. McManus, Michelsen, J. Parkes, A. Colver, “Self-Reported Quality of Life of 8-12-Year-Old Children with Cerebral Palsy: a Cross-Sectional European Study. *Lancet*, 369 (9580), Jun 30 2007, <<https://www.ncbi.nlm.nih.gov/pubmed/17604799>> [accessed 26 December 2017], (pp. 2171-2178)

<sup>12</sup> Raman Scharma, A. Williams, W. Zaw, “The Timing of Gastrostomy Insertion in Children with a Neurodisability: A Cross-Sectional Study of Early versus Late Intervention”, *BMJ Open*, Vol. 2, Issue 6 (2012), <<http://bmjopen.bmj.com/content/2/6/bmjopen-2012-001793>> [accessed 26 December 2017]

I have already mentioned the, in my view, clear societal limits to overcoming profound disability when confronting medical reality. Medical practice is also similarly constrained. Very often all you can offer by way of care is yourself. In these circumstances you, how you carry yourself, your smile, a gentle friendly word, is the thread upon which the patient and their family hold their hopes. Thus, several times a year, I lead a conversation with the parents of a life-limited child with complex neurodisability, whom I have managed as their consultant for many years – my longest has been for seven years. Perhaps one definition of my professional and medical roles is the slow accumulation of the capital of human trust, between myself, the patient and their families, so that it can be expended at this particular moment.

The purpose of this conversation is to impart that, in spite of all that medical science can presently offer, the child has reached the end of what is possible. Humanely and with compassion, you have to share the facts as they are: sadly, and inevitably, the child's death will occur in the near future. Outside the consultation room, you know this undeniable fact and the role you must play. You pause, collect your thoughts, take a big breath, smile and enter. What you have to impart, you do not want to say, but it is best for the child and their family that it comes from you rather than anyone else. Medically, you have known this child longer than anyone and within this context no one knows as much as you. What they have to hear, you fervently wish somehow to be untrue, but you know it is not.

In a quiet room, with my mobile switched off, I say to the family: "I'm truly sorry, but there is nothing more that can be done." Because of the years of mutual trust that has built up between us, the family know this statement to be true. I feel it is right and best for the children's physician to be the one giving this unfortunate news. Recognising that the moment has come is based upon years of experience and sometimes it is not possible to get it "right". Doctors are fallible and hard-earned trust between the doctor, the child and his/her family will not withstand repeated

misdiagnosis and categorically stated opinions that are subsequently revealed to be wild misjudgements.

This specific situation is clearly difficult not only for the child (if she/he has sufficient awareness and understanding) and the family, but also for the doctor. If one is too insensitive, “too hard”, one cannot do the job properly; but being too sensitive, “too soft”, one cannot do it at all. During the many years of involvement, the patient-doctor relationship between the child, the family and myself evolves and deepens. Thus, having to say those words and hearing myself saying them, is in itself a deeply painful experience. What the death of such a patient means to their physician cannot be easily described. Indeed, from my perspective, for each child, it represents a shattering of my heart.

As a children’s physician I endeavour to do my best for my patients, and willingly bring in those whose skills and knowledge are greater than my own for the patient’s and the family’s good. But there is only so much, within this evolving clinical situation, that can eventually be done. It has long been my practice when the child is clearly deteriorating to bring in another consultant for a second opinion. I do this to protect the child, to give some comfort to the family for the decades to come after the child’s death, and to protect the reputation of my department and myself. Perhaps I have been fortunate, but I have never had a second opinion, in this area, which differed substantially from my own.

Of course, for each child it is just one journey, but for a doctor there are many. Somehow, you must keep your humanity and try to ensure that each patient by their dying and death does not diminish it. How a doctor “protects” themselves from this process is one question they have to address themselves. For my part, I write plays which explore issues related to medical practice, and which have received public performances from 1999 to the present day. Of course, a play allows for different possibilities than generally occur in real life. Being a physician in this situation, one is clearly faced with one’s own limitations as well as that of medical

science. That, however, is the real world, which medicine merely reflects. What would happen though if the physician called in for a second opinion and, when asked by the child's family whether anything, anything at all could be done, instead of saying "I'm sorry", said "Weeel"? What parent under these circumstances would decline such an opportunity, however slight the chances of a successful outcome? Placed within such cut and dry terms, when certain death is the only other choice, I think it would be excruciatingly difficult for any parent to decline. This is the first idea behind the play.

The second idea was inspired by a notable London Underground poster, of the face of Paul, a young man with Down's syndrome.





### **Figure 1. London Underground Poster 2006, with permission from the Down's Syndrome Association**

This poster is also downloadable from the journal website. Seeing this poster for the first time literally stopped me in my tracks. It was produced by the Down's Syndrome Association to raise awareness of disability discrimination. This poster struck a strong chord. I recognised that look in Paul. At all career stages I have attended interviews – from when I was an aspiring medical student to when I became a consultant – where I was there just to make up the numbers, and the “decision” was already preordained. I guess that experience is typical of most doctors and is called “life”. However, a medically qualified doctor will always find a job somewhere. But for Paul, in the poster, this is still far from being the case. It is an injustice that needs to be righted. In my practice I see disability, often profound, on a daily basis, but in 2006 I infrequently encountered it in any media. So I decided to write a play giving a really good part, specifically for an actor with Down's syndrome. This part would not only allow the actor to demonstrate her full acting range, but also in a role that would be central to the drama and drive it.

#### ***A Dog with a Tail at both Ends: Summary***

The play explores a controversial area of medical ethics within paediatric palliative care. Jo is a teenager with Down's syndrome, with profound physical and cognitive difficulties. At the point of death, Jo is given an experimental medical treatment which not only saves her life, but restores all her faculties to the “normal” range. Unfortunately, this treatment leaves Jo confused and isolated within a world that she does not understand. Rather than live in a world which she is ill equipped to deal with, Jo chooses to stop her treatment and consequently reverts to her previous difficulties.

Jo wears a blank mask at the start of the play prior to having the treatment and also immediately before she switches off the treatment. The treatment, though truly a medical “miracle” for Jo, has been a therapeutic failure. What clearly matters is not whether a treatment works, but rather that the patient benefits. Jo’s story is thus a cautionary tale about medical hubris, and the limits of science.

The play is based upon an imagined and speculative treatment, the risks and side effects of which remain unknown and the actual benefits unproven. It may well be that such a treatment proves impossible to implement in the manner described in the play, or is ultimately possible through completely different means. Within this context, the play asks fundamental questions about what limits, if any, should be placed upon medical science's endeavours to “cure disability” for a patient who is not competent to make a decision and for those who are competent to refuse.

As David Pfeiffer commented, “there are still many people who assume that persons with disabilities need professional guidance (actually, control) in order to live a fruitful life”.<sup>13</sup> This play challenges this outdated attitude. The key ethical themes are best interests, autonomy/competency, rights, advancement of science and personhood. The question then arises as to who can make this assessment, taking into account the respect for the patient’s autonomy, best interest and the risk of harm, and where that balance will lie. Ultimately within the play there is only one outcome. Jo has to be allowed her choice – the right to say “No!” By deciding to stop her treatment, Jo challenges the view that disability is a human condition no one would preferably choose. Clearly, it is up to each individual member of the audience to decide if it is the right choice for Jo or indeed, if they were in her position, for themselves.

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<sup>13</sup> David Pfeiffer. “Overview of the Disability Movement: History, Legislative Record and Political implications”, *Policy Studies Journal*, Vol. 21, Issue 4 (Dec 1993), pp. 724-734 (p. 724)

## DISCUSSION

### Drama and Healthcare

There is a long tradition of plays about medical practice. If successful, such a play can bridge both the sciences and the humanities, allowing exploration not only of the medical/scientific aspects, but also of the deeper human feelings provoked by the drama itself.<sup>14</sup> Drama has relatively recently been moving out of the theatre into having a growing role within health care. As Emma Brodzinski suggests, “it is important to acknowledge that arts in health has been developing as a particular mode of practice within the last 30 or so years”.<sup>15</sup> This is a field that is still evolving. The work, whether hospital-based arts practice or community arts, encompasses a range of dramatic and aesthetic practices and can be potentially applied to different contexts. Moreover, in 2007 this has been endorsed at national level. In *A Prospectus for Arts in Health* (co-commissioned by Arts Council England and the Department of Health), the Department of Health’s statement reads:

The department commissioned the Strategic Review of Arts and Health, and accepted its findings. The Department’s policy is that the arts have a major contribution to make to wellbeing, health, healthcare environments, to the benefit of patients, service users, carers, visitors and staff, as well as to communities and NHS as a whole (Arts Council 2007, front cover).<sup>16</sup>

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<sup>14</sup> Kirsten Shepherd-Barr, *Science on Stage: From Doctor Faustus to Copenhagen*, (Princeton: Princeton University Press, 2006), p. 155-181

<sup>15</sup> Emma Brodzinski, *Theatre in Health and Care*, (London: Palgrave MacMillan, 2010), p. 10

<sup>16</sup> Arts Council. *A Prospectus for Arts in Health*,  
<<http://www.artscouncil.org.uk/media/uploads/documents/publications/phpYUAXLH.pdf>>  
[accessed 20 January 2011]

However, funding as well as evidence of “benefit” has been an ongoing issue. It is noteworthy and of concern that the recent *High Quality Care for All: NHS Next Stage Review*, led by Lord Darzi (2008), has no explicit reference to arts in health within it.<sup>17</sup>

Within the context of disability and the arts there is greater complexity than merely the medical versus social model. Firstly, when a potential cure for the impairment does arise, when applied, it often does not lead to the desired “happy ending”. Both Sacks (1995) and Gregory (1987) have separately related cases where restoration of sight after decades of blindness has ultimately not been in the patient’s interest leading to adverse outcomes.<sup>18</sup> Secondly, there is the whole issue concerning the nomenclature around disability and disability-related terms. Indeed, some disabled groups have rejected the word “integration” for “mixed ability”. *Realwheels* (2017), a professional theatre company based in Vancouver, is one example of this approach. Other “disability” groups, such as those for the deaf differ even more and seek complete acceptance of their perspective from the non-deaf world. In an eloquent interview on Radio 4’s *Today* programme in 2008, deaf activist Tomato Lichy did “not view deafness as a disability”.<sup>19</sup> Indeed some deaf teenagers would refuse to have a cochlear implant (even if it were an option for them) because they viewed their deafness positively and saw it as central to their personal identity.<sup>20</sup> Failure to be aware of this viewpoint can of course lead to serious professional difficulties between medical/educational professionals and deaf children and their families. In my practice I have also heard a similar distinction of non-disability being made for high functioning Aspergers syndrome.

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<sup>17</sup> Lord Ara Darzi. *High Quality Care for All: NHS Next Stage Review Final Report*, (Department of Health, London, 2008), <[http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\\_085825](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_085825)> [accessed 20 January 2011]

<sup>18</sup> Oliver Sacks, *An Anthropologist on Mars: Seven Paradoxical Tales*, (London: Picador, 1995), pp. 102-144; R. L. Gregory, “Blindness, Recovery from”, in *The Oxford Companion to the Mind*, ed. by R. L. Gregory (Oxford: Oxford University Press, 1987), pp. 94-96

<sup>19</sup> Rebecca Atkinson. “Is Deafness a disability?” (BBC, 2008) <[http://www.bbc.co.uk/ouch/features/is\\_deafness\\_a\\_disability.shtml](http://www.bbc.co.uk/ouch/features/is_deafness_a_disability.shtml)> [accessed 28 July 2011]

<sup>20</sup> Lucy Wallis, “Living Outside the Hearing World”. (BBC News, 6 February 2012) <<http://www.bbc.co.uk/news/magazine-16855655>> [accessed 6 February 2012]

This invokes the concept of a hierarchy of disability, a hierarchy between different forms of disability. This perceived hierarchy also raises the question why the curious omission of mental retardation/learning difficulty from most lists of potential therapeutic benefits afforded by stem cells.<sup>21</sup> I do not have a clear answer to this question. I wonder whether it is due to powerful memories of another now discredited state intervention to “cure” mental retardation through state sponsored eugenic policies of the late nineteenth and the first half of the twentieth centuries. From 1899, ten states in the US began compulsory sterilisation of the mentally handicapped, a practice that was subsequently upheld by the US Supreme Court in 1927. Long before the notorious term *lebenswertes Leben* (life worthy of life) and the euthanasia programme of Nazi Germany, other developed Western countries supported this.<sup>22</sup> Of all disabilities, mental retardation/learning difficulty is perhaps one that strikes most at the heart of our common humanity. Perhaps, if included, presently speculated attempts to “cure” it would say more about the society’s true attitude and would question the society’s perceived worth of such human beings.<sup>23</sup>

### **The Role and Journey of the Playwright/Paediatrician**

In this paper I speak solely as a playwright/paediatrician. Within the huge, evolving and at times controversial field of disability studies, it is not possible for me to know or cover all areas. I also acknowledge that, occasionally, the language used within

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<sup>21</sup> G. Martino, G. Pluchino, “The Therapeutic Potential of Neural Stem Cells” *Nature Reviews. Neuroscience*. Vol. 7, Issue 5 (May 2006), <<https://www.ncbi.nlm.nih.gov/pubmed/16760919>> [accessed 26 December 2017], pp. 395-406; S. Chandran, “What are the Prospects of Stem Cell Therapy for Neurology?”, *BMJ*. 337, <<http://www.bmj.com/content/337/bmj.a1934>> [accessed 26 December 2017], pp.1325-1327; K. Park, J. Ourednik, V. Ourednik, “Global Gene and Cell Replacement Strategies via Stem Cells”, *Gene Therapy*, Vol. 9 (2002), <<https://www.nature.com/articles/3301721>> [accessed 26 December 2017], pp. 613-24

<sup>22</sup> R. Gellately, *Lenin, Stalin and Hitler. The Age of Social Catastrophe* (London: Jonathan Cape, 2007), p. 331; S. Kühl, *The Nazi Connection; Eugenics, American Racism and German National Socialism* (Oxford: Oxford University Press, 1994), p. 24

<sup>23</sup> Ruth Hubbard, “Abortion and Disability: Who Should and Who Should not Inhabit the World?”, in *The Disability Studies Reader*, ed. by L.J. Davis (London: Routledge, 2006), pp. 93-105

this paper, based on irrefutable medical realities, might jar against the sensitivities of certain readers, who are approaching this area from an equally valid, but different perspective and viewpoint than my own. In my line of work cures are rare. My role is to ensure that, in spite of their many and evolving medical conditions, my patients live as full lives as they can, with the minimal medical involvement necessary to help them achieve this. In over twenty years of working as a clinical doctor I have learnt that the practice of medicine ultimately boils down to personal interactions – how they are prepared for, conducted, perceived, recorded in writing and lastly remembered by the participants themselves. I had a “traditional medical training” and did not benefit from the enlightened reforms, particularly concerning the development of communication skills, heralded by *Tomorrow’s Doctors*.<sup>24</sup> However, I have been writing plays since before I qualified and this process has considerably helped me to reflect on how we as doctors communicate. Of course, for some health professionals, irrespective of training and time spent upon reflection, it is a skill they just cannot master.

I believe that the practice and study of the arts considerably enriches the medical practitioner, and ultimately makes them better for the patient and the families which they are endeavouring to serve. For me the challenging journey of the playwright/paediatrician leading to the performance of my play serves this greater purpose. The arts clearly have an important role to integrate and be representative of the community they serve.

## Results

For the 2010 performance at the Royal College of Paediatrics and Child Health Spring Meeting a post-performance questionnaire was included within the

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<sup>24</sup> *Tomorrow’s Doctors. Outcomes and Standards for Undergraduate Medical Education*. (London: General Medical Council, 1993), <[https://www.gmc-uk.org/Tomorrow\\_s\\_Doctors\\_1214.pdf](https://www.gmc-uk.org/Tomorrow_s_Doctors_1214.pdf) 48905759.pdf> [accessed 26 December 2017]

programme of the play. Before the play started, I introduced myself to the audience as the play's author and asked them to complete the questionnaire (Table 1).

Table 1: Post-Performance Audience Questionnaire
1) Should scientists be developing this treatment?
2) Should Jo should have been given the treatment and why?
3) Should Jo have been allowed to stop her treatment?
4) Is drama a useful way of exploring these issues?
5) Suggested future topics
6) Category: medical student, trainee paediatrician, paediatrician, member of the public
7) Any other comments

21 questionnaires were returned: paediatricians (13), a trainee paediatrician (1), members of the public (5), a medical student (1) and not stated (1).

All 21 agreed that drama was a useful way of exploring these issues. Comments included: "Things can be said in a more direct way in a play" and "Most definitely it speaks to the head and the heart." One member of the public stated: "As a parent of a child with a life-limiting condition, it shows all sides of the argument." A paediatrician wrote: "Very thought provoking. Not sure there is a correct answer."

Next, concerning whether scientists should be developing this treatment: 15 were in favour. 10/12 paediatricians, 4/5 members of the public. One commented: "Were there other treatments that at one time were controversial but later proved useful and beneficial?" One member of the public, later disclosing themselves to be a parent of a child with special needs, said "no". There was one undecided person stating "very questionable – maybe after tracks of research are more easily acceptable".

As to whether Jo should have been given the treatment, 12/21 said "yes", 5 said "no" (3 paediatricians, 1 trainee paediatrician and 1 medical student). 2 members of the public said "yes and no", one of whom was the parent of a child with special needs, who wrote: "It gave her the chance to give her opinion and make her

own decisions.” One paediatrician and one member of the public refused to answer, the latter writing: “Tough call. Her parents wanted the best for her. They know the risks.” Those saying “yes” recognised the question was difficult; the answer, however, was not clear cut.

3 paediatricians wondered if more support to Jo would have led to a different outcome, but 1 of this group then contradicted themselves stating “not in this way”. One medical student said “no” giving general reasons as disagreeing with stem cell therapy or that “doctors should not be playing God”. One paediatrician saying “no” poignantly stated: “I have a brother with Down’s syndrome. He was made that way and he has adapted and is happy.”

Finally, suggested future topics for drama included “other ethical dilemmas that arise every month in paediatric practice” and are listed in Table 2:

Table 2: List of Future Topics
Cancer/ depression suicide
Technology and life support – neonatal ICU, ventilation for DMD
Dilemmas of extremely premature infants
Relationship between parent, patient and multiple teams involved in that child's care and how much they do/do not involve the child
Withdrawal of life-sustaining treatment/Giving bad news
Genetic implications of disease
Other ethical dilemmas
Transplantation of whole limbs and hands etc.
Post code lotteries
Use of limited resources
Sexual rights of disabled teens
Topics that arise every month in paediatric practice
Addiction
Saviour siblings argument

Surprisingly, there was not a single suggestion on child protection or child abuse.



### ***Flowers for Algernon***

Of course the theme of healing mental retardation/learning difficulty is not entirely new. It was only after the play's first public performance in 2008 that Daniel Keyes' *Flowers for Algernon* (1959) was brought to my attention – a work of which I had until then been completely unaware. *Flowers for Algernon*, although in some ways similar, nevertheless has clear differences from *A Dog with a Tail at both Ends*. In *Flowers for Algernon*, Charlie Gordon, a middle aged man with severe learning difficulties, chooses to have an unspecified treatment that triples his IQ and gives him for a time fearsome intellectual powers. Unfortunately, in spite of Charlie's wishes "to be smart", his treatment therapeutically fails and he ends up as he once was before, but with the knowledge that once he had "been smart". In *A Dog with a Tail at both Ends* Jo is younger, with far greater intellectual and physical difficulties, but is not able to give any informed decision or choice concerning this treatment. For Jo, her intellectual recovery is in comparison more modest and never places her IQ above "normal". (Of course, this is just a guess, but were such an intervention possible, I feel Jo's would be the more likely therapeutic outcome.) Jo does not benefit and ultimately chooses to stop.

In both plays there is conflict between doctors. The important and crucial differences between my play and *Flowers for Algernon* revolve around the issue of patient choice and consent. Charlie agreed to the procedure and wished "to be smart". Jo had no direct input into the decision making process.

### **Some ethical issues**

The play is based upon an imagined and speculative treatment, the risks and side effects of which remain unknown and actual benefits unproven. It may well be that such a treatment proves impossible to implement in the manner described in the *Postgraduate Journal of Medical Humanities*, 4 (2017): 2-31

play, or is ultimately possible through completely different means. Within this context, the play asks fundamental questions about what limits, if any, should be placed upon medical science's endeavours to "cure disability" in a patient who is not competent to make a decision and to give their opinion.

The issue of Jo's subsequent competence and rights as a teenager to give an informed decision goes beyond the matter that she is fifteen years old and therefore underage. A large part of the current debate on child health care is around this point. But, as Archard puts it: "This is all about finding the competence to fit the right and the age to fit the competence. It does not amount to a case against the view that reaching a given age may be a reliable enough indication that the person has achieved the requisite competence."<sup>25</sup>

In the play Jo's initial unhappiness with her treatment is seen by her parents as her being "silly". Jo's view ultimately firms up to a clear decision to refuse to continue her treatment. Her previous doctor Cathy understands and respects this, but Jo turns down her offer to discuss this on her behalf with John. In a later conversation between Jo and John, John does not believe her and considers "carrying on" as the only possible option. Jo, in her frustration and anguish, tries to destroy the controller. John tries to stop her, and in the struggle that follows, Jo accidentally kills John. Jo is then arrested and imprisoned – with her (to her very real) toy elephant Eddy distressingly taken away from her. It is then only through the intervention of a judge – the same one who, coincidentally (but at that time choosing not to see her), had allowed her treatment to start in the first place – that she carries out her decision and is protected from further legal prosecution as she reverts to her previous state.

However, this play reflects a purely speculative treatment. All it can do is set the scene for fuller debates and discussions if and when such treatments were to be

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<sup>25</sup> David Archard, 2nd edn, *Children Rights and Childhood* (London: Routledge, 2004), p. 89

brought forward for evidence-based clinical trials and possible generalised introduction. It does, however, omit the issue of funding the treatment, especially in long term conditions, which is a significant ethical issue in its own right.

There are two aspects of the play that ring completely true to current practice. These are the environment of palliative care and the weight that is given to the voice of a child concerning decisions involving their care. This environment is encountered daily within medical practice. A brief discussion is therefore given in the following sections.

### **Palliative care**

End-of-life care is an inevitable part of medical practice. As medical science has advanced and the ethical environment within which it is practiced developed, it too has evolved, becoming an acknowledged speciality in its own right, with its own institutions and continuing to advance its code of practice. Paediatric data in this area is still limited, however a recent study in adult metastatic non-small-cell carcinoma demonstrated that end-of-life care as well as reducing aggressive care at the end of life, actually prolongs patient survival.<sup>26</sup>

There is some published work on paediatric end-of-life care. Acknowledging the deeply emotive environment of this area of practice, the emphasis lies upon the physician's recognition of the limitations of medical interventions. The open acknowledgement to the patient's family of imminent death and the futility of continued medical intervention are necessary before removing the barriers to death.<sup>27</sup> Of course, all any physician can do is give his/her best opinion and thus

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<sup>26</sup> J.S. Temel, J. A. Greer, A. Muzikansky et al. "Early Palliative Care for Patients with Metastatic Non-Small-Cell Lung Cancer". *New England Journal of Medicine*, Vol. 363, Issue 8 (August 2010), <<https://www.ncbi.nlm.nih.gov/pubmed/20818875>> [accessed 26 December 2017], pp. 733-42

<sup>27</sup> M. Levetown, M. M. Pollack, T. T. Cuerdon, U. E. Ruttimann, "Limitations and Withdrawals of Medical Intervention in Paediatric Critical Care", *JAMA*, Vol. 272, Issue 16 (26 October

giving a prognosis is an imprecise art. In the above study 17% of such cases, where medical care was withdrawn, survived to discharge.

In 2004 The Royal College of Paediatrics and Child Health (RCPCH) published guidelines concerning end-of-life palliative care under the title *Withholding or Withdrawing Life-Sustaining Treatment in Children: A Framework for Practice*. This document defines five situations where active medical care can be withdrawn, namely, the brain-dead child, the permanent vegetative state, the “no chance situation”, the “no purpose situation” and lastly the “unbearable situation”.<sup>28</sup> It clearly emphasises the health care professional’s role stating: “Treatment generally requires cooperation. The Health Care Team must always act in the child’s best interests. The Health Care Team does not inflict treatment on children just because a treatment becomes available, but always introduce treatments for the benefit of the child, withdrawing them when they are no longer of benefit.” This sentiment appears in the updated 2014 guidelines *Making Decisions to Limit Treatment in Life-Limiting and Life-Threatening Conditions in Children: A Framework for Practice*. The 2014 guidelines now include “a category that formally acknowledges the wishes and preferences of those young people who are able to make decisions for themselves, albeit with the support of their families and professionals.”<sup>29</sup>

I have already mentioned my use of second opinions to provide the best possible care within an end-of-life situation. In the play, John, the doctor giving the second opinion, was acting unethically according to current guidelines as he had not previously declared a research interest in this area, which could compromise his

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1994), <<https://www.ncbi.nlm.nih.gov/pubmed/7933372>> [accessed 26 December], pp. 1271-1275

<sup>28</sup> *Withholding or Withdrawing Life-Sustaining Treatment in Children: A Framework for Practice*, 2nd edn (Royal College of Paediatrics and Child Health, 2004), p. 10

<sup>29</sup> *Making Decisions to Limit Treatment in Life-Limiting and Life-Threatening Conditions in Children: A Framework for Practice* (Royal College of Paediatrics and Child Health, 2014), <[http://adc.bmj.com/content/100/Suppl\\_2/s1](http://adc.bmj.com/content/100/Suppl_2/s1)> [accessed 17 September 2017]

judgement.<sup>30</sup> He was also wrong in the manner in which he answered the parents' understandable question "whether anything, anything at all can be done". His deliberately vague reply suggested some possibility of hope for the patient's family when there was no evidence to support this view.

John's unhelpful second opinion raises the question as to how far paediatricians should co-operate with unproven treatments, or where information is limited, neither conclusively proving nor disproving potential benefit. With the ongoing development of the evidence base, this is an evolving debate. For as one of the audience related: "Today's unproven treatment might be tomorrow's standard therapy". The general duty doctors have to serve their patients' interest is open-ended and non-specific. Often there may not be "the right response", only alternative appropriate responses. Doctors are not automatically obliged to co-operate in trying an unproven therapy, even when the patient's request to use it is reasonable and the funding is available.<sup>31</sup> However, there is generally felt to be a presumption in favour of co-operating with patients who are extremely ill.<sup>32</sup>

This is of course an emotional and stressful situation for all concerned. There are, however, limits to medical knowledge and its capacity to heal. In this situation, it is often not possible for the child's family and the medical professionals to agree on future management of the child and what is in the child's best interest. If after further long conversations and input of other independent medical opinions, the disagreement still persists, ultimately it becomes a matter for the court. (This happened in my own hospital in 2016) A well-known example is the 2017 Charlie Gard case, where his doctors felt further treatment would be futile and Charlie's parents pursued a legal challenge. In this quest the parents were endorsed by

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<sup>30</sup> East Midlands Cancer Network, <[www.eastmidlandscancernetwork.nhs.uk](http://www.eastmidlandscancernetwork.nhs.uk)> [accessed 10 July 2011]

<sup>31</sup> C. Yeoh, E. Kiely, H. Davies, "Unproven Treatment in Childhood Oncology: How Far Should Paediatricians Co-operate?" *Journal of Medical Ethics*; Vol. 20 (1994), pp. 75-76.

<sup>32</sup> J. Jackson, "Unproven Treatment in Childhood Oncology: How Far Should Paediatricians Co-operate? Commentary", *Journal of Medical Ethics*, Vol 20 (1994), pp. 77-99

worldwide social media support (as well as from President Trump and the Pope) for a completely unproven experimental treatment that had never been tried with Charlie's form of the condition.<sup>33</sup>

In the play, Cathy, Jo's initial consultant, strongly disagrees with John's second opinion about a potential new therapy. Inevitably, the parents strongly wish for this treatment even though there is no scientific data to inform their decision or John's recommendation of it. John does have a full discussion with the parents about the uncertainties of the speculative treatment, as well as offering time for them to reconsider their original decision to initiate it. Once that parental decision is reaffirmed, a judicial review is requested to decide, given the doctors' fundamental disagreement and the highly controversial nature of the procedure. The judge, without seeing Jo, grants permission for the procedure to occur under the protection of the court. At that point, Cathy withdraws from any clinical involvement, the parents being informed of this and her reasons explained to them. The parents still wish for the procedure to occur and it is only sometime afterwards that Cathy is invited to rejoin the clinical team and becomes involved in Jo's recovery.

## **Performances**

From the outset, this play was written with the clear intention of having Jo played by an actor with Down's syndrome. However, in spite of my utmost efforts, this has not yet proved possible.

I have had the play performed after five rehearsal/performance cycles by three different drama groups between 2007 and 2010. I had a rehearsed reading of the play in Stratford upon Avon in 2007 and then a first full public performance by final-year University of Northampton drama students at the University of Birmingham

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<sup>33</sup> R. Hurley, "Who was fighting for Charlie Gard?" *BMJ* (2017) 358:j3675, <<http://www.bmj.com/content/358/bmj.j3675>> [accessed 26 December 2017]

in the summer of 2008. The play was then taken forward by ARTE, the University of Birmingham Medical Student Drama Society, first for a short run in spring 2009, and secondly with a cut down forty-five-minute version at the 2009 Inspiring Transformations' International Drama Conference at Northampton University.

I have endeavoured in vain since 2006 to persuade inclusive and other theatre companies both within the UK and abroad to perform this play. I have lost count of the number of unanswered emails and phone calls I have made. The few replies I have had have been discouraging. One particularly well known UK-based inclusive theatre group, after I had offered them free use of the play, informed me that they had their own "in-house" writers and were not interested in taking or considering work from outside their company. Attempts to ask that details of the play be passed on to other companies that might be interested proved unsuccessful. Repeated contacts have not elicited any replies. I spent eighteen months working with a nationally renowned University English Department on a grant application to a well known grant provider, to fund this with professional actors one of whom has Down's syndrome. A "warm up" performance at the prestigious 2010 Royal College of Paediatrics and Child Health Spring Meeting was part of this proposal. Unfortunately, our application was rejected and instead a powerful performance was given by medical student actors from the University of Birmingham. (Figure 2)



**Figure 2: Performance photograph from the 2010 Royal College of Paediatrics and Child Health Annual Meeting**

## Conclusion

*A Dog with a Tail at both Ends* is based upon a presently speculated medical intervention which might in the future become a therapeutic reality. It gives the opportunity for an actor with Down's syndrome to play a meaningful leading role. (I do hope one day to have an actor with Down's syndrome play the part of Jo, but funding and other attempts have so far been unsuccessful.) The play fundamentally challenges the medical model of "cure" being a resetting of the disabled patient to a preconceived set of physiological values which arbitrarily define "normality".

Drama brings to the audience new perspectives and powerful insights. I hope that future plays on different child health themes will also be publicly performed.

As a children's physician, I believe the final words should be from Cathy, Jo's longstanding community consultant paediatrician, which conclude the play.

CATHY: You know, I never stop admiring my patients and especially their parents or carers. I'd be so bloody angry if it was to happen to my



child, but that's something I've very rarely seen in my experience. All love their child for who they are, not mourn what they'll never be. They're all better human beings than I am, or ever will be.

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I would be happy to discuss future performances and further development with anyone who is interested.

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