published in British Medical Journal,
02 April 2025

link to British Medical Journal article [1]

Healthcare services, patients, and families can work better together to improve care transitions, writes Helen Cowan

My husband lives with a spinal cord injury. Hospital admission can be traumatic when I’m excluded despite being his carer.1 [2] I’m privy to information about his care that can’t be gleaned in a single handover with clinicians. I’ve felt unwelcome during the admission process, and healthcare staff haven’t treated me as an expert partner in care. Transitions involve patients and families moving between different clinical contexts—but too often their experiences and expertise are lost or undermined in the process.

Problems with admissions and transition are seen across care settings and patient groups. Al Aynsley-Green, the first national clinical director for children in government, has expressed his concerns about patients receiving chaotic care and scant communication, which is often inappropriate for their age group or condition. He tells of a young woman with a complex health condition being cared for in a cramped overflow hospital bay alongside older people with dementia and then in a single room on a male ward. Her mother felt compelled to stay at the bedside.2 [3]

Follow-up is also a problem, and long gaps in care are common. For young people, this often reflects the separation and delayed transition between child and adult services. The Association for Young People’s Health describes children falling “down the gaps” in the transition to adult healthcare services.3 [4] Disputed responsibilities, delays, “cost shunting,” and “turf wars” between services are noted problems.4 [5] This leaves young people “lost in transition.”5 [6]

Transitions of care can feel like entering unknown territory and can discourage patients from continuing their care. From a mental health perspective, for example, young adulthood is already a vulnerable time, with developmental transition and increased incidence of mental illness.6 [7] Disengagement from care is more likely in this period. Only a quarter of young people make the transition from child and adolescent mental health services to adult services.7 [8]

Putting the family, or those who matter most to the patient, firmly at the centre of the transition process is key to improving experiences for vulnerable patients. For example, as a care home nurse I've seen the distress, confusion, and delirium that can result when an older person with dementia is admitted to hospital. The journalist Nicci Gerrard has written about the experience of her father, who had Alzheimer's, when he was admitted to hospital with an infection. On admission he was articulate and able; weeks later he emerged immobile, incoherent, and incontinent.8 [9] She argues that if his family members had been allowed to stay with him and maintain social connection, he would not have declined so rapidly.

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This experience prompted Gerrard to set up "John's campaign," which asks for carers of people with dementia to have the same rights as parents of sick children.9 [10] This would allow them to accompany them in hospital, to be their "cognitive ramps," and to advocate on their behalf as experts in their experience. More than 1500 healthcare institutions have made pledges to support John's campaign, but this isn't enough. Pledges can be forgotten, and families may be unaware that they exist.

Those involved in John's campaign welcomed the Care Quality Commission's recent rules on visiting, which explain what providers must do to respect the right of patients to receive visits and be accompanied to appointments by a family member, friend, or advocate.10 [11] John's campaign actively supports work towards an NHS care partner policy, which recognises a care partner chosen by a patient to help them while in hospital.11 [12]

The campaign is now calling for a legal right for the person with dementia to maintain contact with at least one person, known as their "care supporter," in health and care settings. This is sometimes referred to as Gloria's law, after the actor Ruthie Henshall's mother, who died while separated from family during the covid pandemic. Gloria's law was introduced to the last parliament by a cross party group of MPs.12 [13]

Right teams, right time

As well as work with families and carers, transitions require connection and collaboration between organisations, with a particular need to bridge the gaps between health and social care. During the pandemic I worked as a care home care coordinator, communicating with GPs, pharmacists, care home staff, residents, and families. This coordination role involved making advance care plans, arranging covid vaccinations, facilitating medication reviews, and sometimes just listening to stories of distress, despair, and heartbreak.

I was uniquely placed to see the overall picture, from clinical care to how social interactions can support wellbeing. I supported shared decision making, coordination of multidisciplinary teams, and the weekly care home ward round. This was especially important at times of transition such as admission to the care home or transfer to or from hospital, when I could act as an advocate for the patient or family, helping "people make the right connections, with the right teams at the right time."13 [14] I support expanding the adoption of care coordinator roles to work with care homes as part of the Enhanced Health in Care Homes scheme.14 [15]

Sometimes a transition in care may not be appropriate or necessary. Of emergency admissions to hospital from care homes, 41% are for conditions that are treatable or preventable outside a hospital setting or that could have been caused by poor care or neglect.15 [16] We need to have conversations about whether these transitions really are necessary and how they could be better managed.

When transitions are needed we must consider how services, patients, and families can work better together. Most importantly, we must allow significant others to be key partners in improving the experience of care transitions.

Footnotes

- Competing interests: None.

- Provenance: Not commissioned; not externally peer reviewed.

References

1. ? [17]
    1. Cowan H
    . Why care matters. BMJ2018;361:k2385. doi:10.1136/bmj.k2385. pmid:29899120
    FREE Full Text [18]Google Scholar [19]

2. ? [20]
    Aynsley-Green A. Why we need more compassion in health care. TEDx Talks, YouTube. 2024. https://www.youtube.com/watch?v=4k07xtuyPpw [21]

3. ? [22]
    Association for Young People’s Health. Young people facing transition between services still face systemic difficulties. Jun 2023. https://ayph.org.uk/young-people-facing-transition-between-services-still-face-systemic-difficulties/ [23]

4. ? [24]
    University of Birmingham, College of Social Sciences. Why are we stuck in hospital? 2023. https://www.birmingham.ac.uk/documents/college-social-sciences/social-policy/publications/why-are-we-stuck-in-hospital.pdf [25]

5. ? [26]
    1. Medforth N
    . Young people lost and found in transition?Compr Child Adolesc Nurs2023;46:177-9. doi:10.1080/24694193.2023.2201317. pmid:37639677
    CrossRef [27]PubMed [28]Google Scholar [29]

6. ? [30]
    1. Broad KL,
    2. Sandhu VK,
    3. Sunderji N,
    4. Charach A
    . Youth experiences of transition from child mental health services to adult mental health services: a qualitative thematic synthesis. BMC Psychiatry2017;17:380. doi:10.1186/s12888-017-1538-1. pmid:29183289
    CrossRef [31]PubMed [32]Google Scholar [33]

7. ? [34]
    1. Appleton R,
    2. Connell C,
    3. Fairclough E,
    4. Tuomainen H,
    5. Singh SP
    . Outcomes of young people who reach the transition boundary of child and adolescent mental health services: a systematic review. Eur Child Adolesc Psychiatry2019;28:1431-46. doi:10.1007/s00787-019-01307-7. pmid:30850925
    CrossRef [35]PubMed [32]Google Scholar [36]

8. ? [37]
    Gerrard N. My father entered hospital articulate and able. He came out a broken man. Guardian 29 Nov 2014. https://www.theguardian.com/society/2014/nov/29/nicci-gerrard-father-dementia-hospital-care-elderly [38]

9. ? [39]
    Gerrard N. John’s Campaign to transform dementia care is gaining powerful support. Guardian 25 Jul 2015. https://www.theguardian.com/society/commentisfree/2015/jul/25/johns-campign-dementia-care [40]

10. ? [41]
    Care Quality Commission. Regulation 9A: Visiting and accompanying in care homes, hospitals and hospices. 26 Apr 2024. https://www.cqc.org.uk/guidance-providers/regulations/regulation-9a-visiting-and-accompanying [42]

11. ? [43]
1. Liverpool Heart and Chest Hospital. Care Partner. 2024. https://www.lhch.nhs.uk/care-partner [44]
Google Scholar [45]

12. ? [46]
Care Rights UK. Gloria's Law: our fight for a new legal right to a care supporter. 2024. https://www.carerightsuk.org/glorias-law [47]

13. ? [48]
NHS England. Workforce development framework for care coordinators. 2023. https://www.england.nhs.uk/long-read/workforce-development-framework-for-care-co-ordinators/ [49]

14. ? [50]
NHS England. Expanding our workforce. https://www.england.nhs.uk/gp/expanding-our-workforce/#personalised-care-care-coordinators-health-and-wellbeing-coaches-and-social-prescribing-link-workers [51]

15. ? [52]
Health Foundation. Emergency admissions to hospital from care homes: how often and what for? Jul 2019. https://www.health.org.uk/publications/reports/emergency-admissions-to-hospital-from-care-homes [53]

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&utm_source=twitter#ref-13 [15] https://www.bmj.com/content/389/bmj.r650?utm_campaign=usage&utm_content=tbmj_sprout&utm_id=BMJ005&utm_medium=social&utm_source=twitter#ref-14 [16] https://www.bmj.com/content/389/bmj.r650?utm_campaign=usage&utm_content=tbmj_sprout&utm_id=BMJ005&utm_medium=social&utm_source=twitter#ref-15 [17] https://www.bmj.com/content/389/bmj.r650?utm_campaign=usage&utm_content=tbmj_sprout&utm_id=BMJ005&utm_medium=social&utm_source=twitter#xref-ref-1-1 [18] https://www.bmj.com/lookup/ijlink/YTozOntzOjQ6InBhdGgiO3M6MTQ6Ii9sb29rdXAvaWpsaW5rIjtzOjU6InF1ZXJ5IjthOjQ6e3M6ODoibGlua1R5cGUiO3M6NDoiRlVMTCI7czoxMToiam91cm5hbENvZGUiO3M6MzoiYm1qIjtzOjU6InJlc2lkIjtzOjE4OiIzNjEvanVuMTJfMjUvazIzODUiO3M6NDoiYXRvbSI7czoyMjoiL2Jtai8zODkvYm1qLnI2NTAuYXRvbSI7fXM6ODoiZnJhZ21lbnQiO3M6MDoiIjt9 [19] https://www.bmj.com/lookup/google-scholar?link_type=googlescholar&gs_type=article&author[0]=H+Cowan&title=Why+carers+matter&publication_year=2018&journal=BMJ&volume=361 [20] https://www.bmj.com/content/389/bmj.r650?utm_campaign=usage&utm_content=tbmj_sprout&utm_id=BMJ005&utm_medium=social&utm_source=twitter#xref-ref-2-1 [21] https://www.youtube.com/watch?v=4k07xtuyPpw [22] https://www.bmj.com/content/389/bmj.r650?utm_campaign=usage&utm_content=tbmj_sprout&utm_id=BMJ005&utm_medium=social&utm_source=twitter#xref-ref-3-1 [23] https://ayph.org.uk/young-people-facing-transition-between-services-still-face-systemic-difficulties/ [24] https://www.bmj.com/content/389/bmj.r650?utm_campaign=usage&utm_content=tbmj_sprout&utm_id=BMJ005&utm_medium=social&utm_source=twitter#xref-ref-4-1 [25] https://www.birmingham.ac.uk/documents/college-social-sciences/social-policy/publications/why-are-we-stuck-in-hospital.pdf [26] https://www.bmj.com/content/389/bmj.r650?utm_campaign=usage&utm_content=tbmj_sprout&utm_id=BMJ005&utm_medium=social&utm_source=twitter#xref-ref-5-1 [27] https://www.bmj.com/lookup/external-ref?access_num=10.1080/24694193.2023.2201317&link_type=DOI [28] https://www.bmj.com/lookup/external-ref?access_num=37639677&link_type=MED&atom=%2Fbmj%2F389%2Fbmj.r650.atom [29] https://www.bmj.com/lookup/google-scholar?link_type=googlescholar&gs_type=article&author[0]=N+Medforth&title=Young+people+lost+and+found+in+transition?&publication_year=2023&journal=Compr+Child+Adolesc+Nurs&volume=46&pages=177-9 [30] https://www.bmj.com/content/389/bmj.r650?utm_campaign=usage&utm_content=tbmj_sprout&utm_id=BMJ005&utm_medium=social&utm_source=twitter#xref-ref-6-1 [31] https://www.bmj.com/lookup/external-ref?access_num=10.1186/s12888-017-1538-1&link_type=DOI [32] https://www.bmj.com/lookup/external-ref?access_num=http://www.n&link_type=MED&atom=%2Fbmj%2F389%2Fbmj.r650.atom [33] https://www.bmj.com/lookup/google-scholar?link_type=googlescholar&gs_type=article&author[0]=KL+Broad&author[1]=VK+Sandhu&author[2]=N+Sunderji&author[3]=A+Charach&title=Youth+experiences+of+transition+from+child+mental+health+services+to+adult+mental+health+services:+a+qualitative+thematic+synthesis&publication_year=2017&journal=BMC+Psychiatry&volume=17 [34] https://www.bmj.com/content/389/bmj.r650?utm_campaign=usage&utm_content=tbmj_sprout&utm_id=BMJ005&utm_medium=social&utm_source=twitter#xref-ref-7-1 [35] https://www.bmj.com/lookup/external-ref?access_num=10.1007/s00787-019-01307-7&link_type=DOI [36] https://www.bmj.com/lookup/google-scholar?link_type=googlescholar&gs_type=article&author[0]=R+Appleton&author[1]=C+Connell&author[2]=E+Fairclough&author[3]=H+Tuomainen&author[4]=SP+Singh&title=Outcomes+of+young+people+who+reach+the+transition+boundary+of+child+and+adolescent+mental+health+services:+a+systematic+review&publication_year=2019&journal=Eur+Child+Adolesc+Psychiatry&volume=28&pages=1431-46 [37] https://www.bmj.com/content/389/bmj.r650?utm_campaign=usage&utm_content=tbmj_sprout&utm_id=BMJ005&utm_medium=social&utm_source=twitter#xref-ref-8-1 [38] https://www.theguardian.com/society/2014/nov/29/nicci-gerrard-father-dementia-hospital-care-elderly [39] https://www.bmj.com/content/389/bmj.r650?utm_campaign=usage&utm_content=tbmj_sprout&utm_id=BMJ005&utm_medium=social&utm_source=twitter#xref-ref-9-1 [40] https://www.theguardian.com/society/commentisfree/2015/jul/25/johns-campign-dementia-care [41] https://www.bmj.com/content/389/bmj.r650?utm_campaign=usage&utm_content=tbmj_sprout&utm_id=BMJ005&utm_medium=social&utm_source=twitter#xref-ref-10-1 [42] https://www.cqc.org.uk/guidance-providers/regulations/regulation-9a-visiting-and-accompanying [43] https://www.bmj.com/content/389/bmj.r650?utm_campaign=usage&utm_content=tbmj_sprout&utm_id=BMJ005&utm_medium=social&utm_source=twitter#xref-ref-11-1 [44] https://www.lhch.nhs.uk/care-partner [45] https://www.bmj.com/lookup/google-scholar?link_type=googlescholar&gs_type=article&q_txt=.+Care+Partner.+2024.+https%3A%2F%2Fwww.lhch.nhs.uk%2Fcare-partner [46] https://www.bmj.com/content/389/bmj.r650?utm_campaign=usage&utm_content=tbmj_sprout&utm_id=BMJ005&utm_medium=social&utm_source=twitter#xref-ref-12-1 [47] https://www.carerightsuk.org/glorias-law [48] https://www.bmj.com/content/389/bmj.r650?utm_campaign=usage&utm_content=tbmj_sprout&utm_id=BMJ005&utm_medium=social&utm_source=twitter#xref-ref-13-1 [49] https://www.england.nhs.uk/long-read/workforce-development-framework-for-care-co-ordinators/ [50] https://www.bmj.com/content/389/bmj.r650?utm_campaign=usage&utm_content=tbmj_sprout&utm_id=B

MJ005&utm_medium=social&utm_source=twitter#xref-ref-14-1 [51] https://www.england.nhs.uk/gp/expanding-our-workforce/#personalised-care-care-coordinators-health-and-wellbeing-coaches-and-social-prescribing-link-workers [52] https://www.bmj.com/content/389/bmj.r650?utm_campaign=usage&utm_content=tbmj_sprout&utm_id=BMJ005&utm_medium=social&utm_source=twitter#xref-ref-15-1 [53] https://www.health.org.uk/publications/reports/emergency-admissions-to-hospital-from-care-homes