Dementia or detentia?

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INTRODUCTION

This is a story of interest and concern to all people working in community health and aged care. It is a case study told by the three major parties involved – A Manager Primary Care and Nursing Services, Regional Manager of Aged Care Assessment Team (ACAT) and an Advocate from a Regional Disability Advocacy Service. It highlights a situation that is familiar to many of us whether working in the community or residential facilities. It is a situation that covers a common enough occurrence for older people and outlines what could be viewed as a normal and typical transition for an elderly woman from home care to residential aged care. However, it is not.

OBJECTIVES

Our objective is to let you get to know Mrs B and to tell you what happened to her, how we discovered the injustices, how we attempted to correct them and our experiences and recommendations on the way.

We want to raise areas of care that we need to be vigilant about and remind us all that sometimes we do not do the best by our clients. It is also to jog our memory that often we are the only advocates for elderly people and that this is a serious responsibility.

Our aim for this presentation is to leave you reflecting on this case study and raising your awareness of how things are not always as they seem.

WHO WAS MRS B?

Mrs B was a 92-year-old woman who had been looking after herself in her own home with minimal assistance. She fell whilst going to catch a bus to do some shopping and suffered a # R NOF and L Patella. She was hospitalised in a large Melbourne hospital and rehab centre where she had been assessed by ACAT but had not signed the application, which was signed on her behalf by the social worker undertaking the assessment. It stated that due to cognitive impairment Mrs B was unable to sign. Her relative had invoked the power of attorney and was therefore in charge of Mrs B finances and affairs. Mrs B was transferred by ambulance to a remote rural aged care facility 400+ kms from her home for high-level nursing home care.

Upon arrival in August she was frail and recovering following her fall 8 weeks earlier and she appeared somewhat confused. In her notes it was commented “slight dementia”. Her first words were “There has been a terrible mistake, I have a lovely home in
Melbourne.” Her relative (not immediate family as she did not have any) was present to greet her as she arrived and assured us that she was confused.

Mrs B recovered well and after 8 weeks was ambulant, eating well, and managing her ADLs. However she had a large rash (psoriasis) that would intermittently become angry and flare up. The decision was made to transfer Mrs B from the nursing home into a low level hostel. Upon learning this, Mrs B became very agitated, wanted to go home and her psoriasis flared up. The Residential Care Manager contacted the Aged Mental Health team to obtain a mental health assessment (believing there was an underlying mental health problem). Their report stated there was some mild cognitive impairment but no mental health problem and recommended a reassessment by the Aged Care Assessment Service.

Mrs B was transferred to the Hostel in November. She continued to state that she was well enough to go home. The then Residential Care Manager contacted The Office of the Public Advocate to apply for emergency guardianship on the basis of dementia and that Mrs B would abscond. The Office of the Public Advocate requested an assessment by the ACAT team before the guardianship hearing. The assessment by the ACAT geriatrician stated, “Cognitively Mrs B is impaired to a mild to moderate degree. She has no insight and has previously cancelled services. Nonetheless it would be possible for her to return home if she would accept a CACP to monitor her nutrition and hygiene.”

The Civil Administrative Tribunal hearing was in December Mrs B was not present at the hearing—the Residential Care Manager did not take her, neither did her relative and POA. However, the Residential Manager and her relative were in attendance.

A guardian based in Melbourne 400 kms away (Office of the Public Advocate) was appointed but was limited to decisions concerning accommodation and health care. The Office of the Public Advocate did not visit her—they never met with her or spoke with her prior to the hearing yet the tribunal made a decision that had a massive impact on her life. Her relative retained enduring power of attorney.

The application for guardianship states that the tribunal will usually insist on meeting the person who is believed to have the disability unless it is impossible to do so. As the applicant (Residential Aged Care Manager) the Tribunal expects that you will arrange/facilitate for the person to attend the hearing if possible.

Mrs B was imprisoned in the system—she just wanted her own things back, her money and to return to her own home. Mrs B was denied her basic rights.

**DISCOVERING THE WRONG**

The Residential Manager resigned and in February that year I became more involved with the hostel. Mrs B had terrible psoriasis and an appointment was made with the dermatologist who commented.

That Mrs B has psoriasis which can be stress related. Her relatives tell me that she has dementia although on the occasions that I have seen her this is not evident. I am keen to find out the actual status of her dementia… I am a keen advocate to keeping patients at home.
Our hostel was also due to undergo a complete refurbishment. Residents were asked to complete a form on whether they would like to share a room or make other arrangements during the building program. Her relative (POA) filled out the form saying that at no stage was Mrs B to be discharged from the hostel and the Office of the Public Advocate (OTPA) stated the same. However, Mrs B had accessed the form and wrote one herself sending it to me stating that “she did not wish to share a room, that she wished to go home and that she was not present to represent herself at the guardianship hearing.” A check of our motor vehicle logs and Mrs B’s history confirmed that she did not attend the guardianship hearing—the alarm bells were ringing.

On interview Mrs B’s GPs described Mrs B as “being lucid and gives a reasonable story of being unreasonably detained.” I contacted her previous GP in Melbourne to confirm her previous state of health who confirmed that “she had been a fit and well 92-year-old woman. Yes she had run down the street naked once, but she did have a UTI and was subsequently treated satisfactorily”. The dermatologist treating Mrs B’s psoriasis again confirmed that she believed Mrs B to be lucid.

The Office of the Public Advocate was contacted in writing requesting a review of her current accommodation arrangements in view of her competence, repeated demands to go home and the assessments and comments by other health professionals. This was followed up with a telephone call confirming that we believed that Mrs B should be at home and was competent to do so. We did not get far.

**MUSTERING SUPPORT**

The Regional Manager of ACAT was most supportive, helpful and became involved. Together we rang Mrs B’s Guardian, we visited him in Melbourne and we began the process of more assessments to prove that Mrs B was competent at 92 to be home.

ACAT organised the following assessments to assist with the case:

- Mrs B had a geriatrician assessment who showed her Folstein Mini mental Examination to be 26/30 and who recommended that she return to her home.

- A psychologist assessed Mrs B who scored 27 on the MMSE of which a score of 24 was considered normal. “I have formed the opinion that this lady is imprisoned in the system, because she obeys authority and is not aware of her rights.”

We also spoke to her relative who said “there was no way she would look after or keep contact with her and that she was renting the house out and had packed up her belongings.” She would wipe her hands of the whole relationship. The guardian was not keen on reviewing the case and had been discussing the same with the relatives who were now keen to rent out her home and were doing so over the Easter period.

Despite this, both the ACAT Manager and myself felt that we needed to continue this cause. I spoke to Mrs B suggesting that we contact an advocate for her—she agreed, although was hesitant as she had so many people who were supposed to help her that did not helped and had become distrustful.
ENLISTING SOUTHWEST ADVOCACY (HER STORY)

I was contacted in April 2000 regarding an elderly woman (Mrs B) who the Primary Care Manager felt was being held against her will in their aged care facility. The Primary Care Manager seemed at a loss as to know what to do to help the lady and that progress was blocked by bureaucratic structures that were not serving the best interests of this woman.

My position is as a disability advocate and although Mrs B did not have a defined disability, I believe that the elderly are quite often abused through their vulnerability, as there appears to be no advocacy services available for people in Mrs B’s position.

My first action when I receive any referral is to contact the person about whom the referral is made because regardless of what any family or referring service wants, my only consideration is to the client and it is their instructions that I follow. It is not my role to make a judgement as to whether Orders put in place are beneficial to the client or not. I inform the client of their rights and about the appeal process.

In the Primary Care Manager’s opinion Mrs B had made a full recovery and was being held against her wishes and that numerous assessments had validated her concerns and ACATS. The Manager was of the belief that with services in place the lady would be able to cope at home and informed me that there was a guardianship order in place and that Mrs B's relative had Power of Attorney. She also explained that the relative lived locally (50 km) and that it was very convenient for her if the lady remained where she was.

I contacted Mrs B by telephone, introduced myself and informed her of what my service could offer. She was very distrustful and reluctant to speak over the telephone. However, she agreed to a meeting. On my first visit Mrs B informed me that her relative had control of her bank account and was withholding any money from her. She had signed a Power of Attorney some years ago giving her relative control of her finances in the event of her not being able to administer them herself. She was very angry that her relative had invoked the Power of Attorney. Not only was she withholding any money, she was in the process of renting out the lady’s home and selling off the contents. I informed Mrs B that it was her right to revoke that Power of Attorney if she wished. She stated that she wished to do this and I gave her the form, which she signed. I informed her that as of that moment, her relative no longer had Power of Attorney. She was amazed at how simple it was. She expressed fear of informing her relative and I explained that I would write a letter informing her relative that she no longer had Power of Attorney and I would request that she return Mrs B bank book and receipts for all monies spent. It is worth mentioning that Mrs B had well over one hundred thousand dollars in the bank.

We spoke about the Guardianship Order. She informed me that upon her continued requesting to go home, she had been informed that a Guardianship Order was being sought. She was informed of the hearing date and had prepared herself to attend. On the day she was sitting having her breakfast when a staff member had come and informed her that the hearing was cancelled. Later that afternoon she was informed that she had a Guardian. We all still wonder why they were so afraid of Mrs B attending the hearing.
We discussed her Guardian, appointed by the Civil and Administrative Tribunal. The guardian had never visited Mrs B, never written to her or even phoned her prior to the hearing. We were all astounded that this person who was in control of where this Mrs B lived and her health care, had never made contact with her. As we spoke, it was becoming more and more apparent that an incredible injustice had been done. I had received clear instruction as to what my client wanted—“to go home”. Mrs B signed an authority for me to act for her under her instructions.

On returning to my office I immediately contacted the relative by telephone and informed her Power of Attorney was revoked. I informed her that I would be sending her a copy of the document and a request for Mrs B’s bankbook and receipts to be sent to her. She informed me that if her relative returned to Melbourne, she would not support her in any way. I told her that I had discussed this possibility with Mrs B and that it did not detract from her wish to return home.

I contacted the Office of the Public Advocate to speak to the Guardian. To say that he “hit the roof” when I informed him that the lady had revoked the Power of Attorney is putting it mildly. After a lot of “What right did I have!!?” I reminded him of who his client was. I recall him saying, “What if she goes home and dies”? to which I responded, Mrs B is 92 years old and has spent the last eight months in total misery, if she goes home and dies two days later, at least she will have had two days of happiness. He eventually agreed that new assessments be carried out with a view to Mrs B going home but threatened repeatedly that if Mrs B did not agree to accept services, he would revoke her permission to go home.

We located Mrs B’s old solicitor, who had been quite concerned about her whereabouts and informed him of all the events. He volunteered to inspect Mrs B’s home and establish that no one was living in it and would see her once she was home to establish her legal needs. He would become her Power of attorney for as long as she wanted it. This had been one of the conditions of her going home, even though a person’s financial concerns are not part of the Guardian’s control. There were a few concessions made at the time for the sake of the Mrs B going home, this should not have been the case.

I’ll never forget Mrs B’s words to me, she said

I’ve worked hard all my life to buy my home, I’ve never drank much and I’ve never run round with men and I can’t understand how they can take my home away from me.

Her powerlessness at her situation was frightening.

Although Mrs B was very grateful to me for what I had done, it would never have happened without the Primary Care Managers intervention in the first place and her follow through.

**GOING HOME**

The Regional Manager of ACAT, CEO of our rural health service and myself visited Mrs B’s home in Melbourne and met with her Solicitor. Her house was perfect, it had red geraniums up the driveway, just as she had described. We met and liaised with the CAPS people and discussed her home care.
However, before she could go home (still under a guardianship) we were required to undertake a:

- Physiotherapy assessment for mobility x 2 and written reports
- OT assessment for cooking of meals.
- OT assessment for going shopping and written reports
- Letter from treating GP
- Letter from hostel supervisor

After these assessments were conducted as well as the previous assessments, services were put in place.

Mrs B went home in May, accompanied by two of my staff that went to Melbourne with her. Her relative refused to drive her or accompany her. On arrival in Melbourne a family from across the road ran out to see Mrs B and said they had been worried so much about her, no one ever told them what was going on, no family, no one had ever spoke to them.

**CONCLUSION**

We rang her solicitor and he informed me some time later that Mrs B was managing well. In June the following year at 94 Mrs B had cancelled all services, had revoked her Power of Attorney which was her Melbourne based solicitor who was a wonderful advocate for old people. The Civic Administrative Tribunal had also revoked her Guardianship 12 month later in June.

This entire injustice occurred primarily because the services involved were not listening to their client and were acting on instruction from a family member who may not have been acting in Mrs B’s best interest and had ensured that she had no power to change her situation.

**RECOMMENDATIONS**

1. When a person is unable to sign an ACAT assessment that an advocate should be there to ensure that clients best interests were being looked after both in terms of Power of attorney and also in view of Aged care placement. Our regional ACAT manager thought this to be “singularly inappropriate because Mrs B was competent to make up her own mind”.

2. That someone should speak on behalf of the client and that no guardianship order should be given by the Civil Administrative Tribunal unless they personally have met or spoken to the person for whom the guardianship order is being taken out, ie they should adhere to their own recommendations.

3. That elderly people should have access to advocates in rural and metropolitan areas and that advocacy services should be increased to cover not just disability but incorporate elderly people as well.
**PRESENTER**

_Susan Brumby_ is currently Director Community Services and a member of the executive staff at Western District Health Service, in Hamilton, Victoria. Prior to this she held the position of Manager Primary Care and Nursing Services at Heywood Rural Health overseeing the introduction of broad-based community health services and a refocus away from bed-based services. Sue is a registered nurse, midwife, holds a Diploma in Farm Management, Graduate Diploma in Women’s Studies and is completing her Masters in Health Management. She has also held several prominent positions in the agriculture sector at state and national levels, has managed a beef and wool property, and maintains an active interest in supporting rural and regional communities. Sue is a graduate of the Australian Leadership Program Course 3.