parkinson's australia

SOCIAL WORK WITH OLDER PEOPLE WHO LIVE WITH PARKINSON'S

CASE STUDY

Social workers are an integral part of your care team and through their focus on the whole person, within the context of their environment provide support and advocacy for the person living with Parkinson's and their carers.

Diagnosis journey with a social worker

Social workers are part of a multidisciplinary care team that provide a holistic coordination and case management service. They link together the different elements and systems that are involved in supporting someone's ongoing care and coordinate them to give best-practice support.

Social workers focus on the person, not the condition, and not the symptoms, as the 'person' can get lost in everything Parkinson's. A truly person-centred and directed focus means providing trusted support for you and your carers at your pace, walking alongside you as you both adjust and come to terms with how to live well with the diagnosis.

This also means not pathologising anyone for feeling depressed, or scared, or in denial, but rather recognising and validating these responses to a diagnosis of Parkinson's.

It is also known that a common and early Parkinson's non-motor symptom is unexplained depression. Social workers can help with early intervention and find appropriate supports.

Social workers consider the person within their home and community environment through a comprehensive bio-psychosocial assessment that addresses all aspects of their daily lives.

This includes:

- financial situation and impact
- current or emerging issues regarding transportation and mobility
- supporting emotional wellbeing and mental health issues for both the individual and their care partners and necessary supports
- facilitating access to necessary supports with regards to mobility, feeding speech etc by working with the appropriate allied health professionals
- support with accommodation issues now and into the future, for example accessing in home support, consideration of accommodation options
- supporting carers regarding the impact of grief and loss and carer stress
- educating and supporting individuals to prepare advanced health directives and enduring power of attorney and end of life care.

Some aged care facilities and retirement villages employ social workers on contract, but they are not always embedded in the service.

To contact a spokesperson please email:
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For more information, visit our website at:
www.parkinsons.org.au

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Case study #1: John

John, aged 82, was formally diagnosed with PD in his 70s, although upon looking back, his family recalled the symptoms started years prior. John and his wife were living in a retirement village at the time, with access to a social worker.

Then, John was admitted to the hospital where a medical team recommended that a feeding peg be inserted and that he change to pureed food and thickened liquids due to his swallowing issues. John loved his food and a glass of beer or a scotch when his sons visited him. His view was that if he could not enjoy his food or drink, there was no point left in life. The social worker explored his goals for quality of life and the risks. John decided not to change his diet. He, his wife, their son and the social worker met with the medical team. John expressly made his views clear, recognising the risks. The social worker advocated for John on the principle of dignity of risk, and his rights to dignity and choice.

John was becoming frailer and was at risk of falling. His wife expressed concern as she could not lift him. The social worker explored these issues with John and organised for an ACAT assessment. A package was negotiated for them for in-home support. However, John was reluctant to accept personal care support when showering.

His wife's Alzheimer's also started to worsen: one day she went shopping and became disoriented and lost; on another day she mistakenly ordered 12 bottles of milk. The social worker now worked with both to identify ways to support them in their own home through an ACAT assessment for her and more home help.

John's swallowing issues progressed and he was starting to aspirate when he ate. Eventually, the social worker supported the couple with making a decision to move into aged care and visiting a few facilities.

The social worker supported his wife. She required a great deal of psychosocial support with regards to her own grief at witnessing his decline while also coping with her progressive Alzheimer's. John was able to enjoy his diet for another year before he passed away.

Case study #2: Reg

Reg was aged in his 70s when he came into aged care as his wife could no longer support him at home despite trying so hard. Reg had advanced Parkinson's with quite severe impacts to his mobility and speech.

This particular facility had a part-time social worker. They focused on Reg's transition to aged care, something he did not want and was having difficulty adjusting. They also supported his wife who was feeling guilty at having to make this difficult decision. She kept trying to work out how to have Reg return home but knew this was not possible. Through a combination of individual counselling and working with the couple together, Reg and his wife were able to come to terms with the decision, and to shift their focus to the present and the quality of their life together.

There was a marked shift for both who spent time together memory-making with their children and grandchildren. Individual support for each continued as Reg's symptoms deteriorated. He was increasingly aspirating, mobility had decreased significantly and his ability to communicate lessened. The social worker provided emotional support, identitified and advocated for practical tools and strategies to assist Reg. They also collaborated closely with the Facility Manager about Reg's needs.

The social worker had been there from the day Reg entered the facility and was able to provide grief and loss support for both him and his wife through their journey, and importantly, to be a support to his wife following his passing.

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Case study #3: Jean

Jean was diagnosed with Parkinson's in her 50s. She was a career woman who loved her job working in a legal firm. She finally retired at age 70. Her Parkinson's symptoms began to deteriorate to the point where she had significant mobility issues and pain. She had carers in every day to assist with her daily living. Following an incident where she was hospitalised she entered aged care. Jean was distraught at having to leave her independence.

In the aged care facility, she was referred to the social worker who met with her weekly to provide psychosocial support regarding her grief and loss in particular. However, there were other issues that arose in terms of the need for advocacy regarding some of her care needs. Jean was also referred to a mental health practitioner for her ongoing depression. Thus, Jean had the support of an individual counsellor, but also the social worker who had a broader perspective of her overall needs. This included advocating for support to improve the quality of life of Jean with staff.

Jean was increasingly viewed as being difficult due to her 'behaviour's' which included calling out and being 'demanding'. The social worker's role here was to educate staff about the profound sense of loss of control that Jean was experiencing and that she was at times terrified. The focus was on helping the staff understand the reasons behind the behaviour and that Jean required kindness and reassurance and support. The social worker's advocacy was ongoing regarding this, emphasising this in each of the case notes, talking to staff and the clinical management team.

The social worker also advocated for increased Physiotherapy and Occupational Therapy (OT) support and worked with the OT to identify ways of better assisting Jean, who was immobile and never left her chair.

This included trialling a regency chair where she could be taken outside of her room and being there with her when she was put into the hoist as she found this uncomfortable and frightening.

The social worker was able to consider broader quality of life issues, which included her environment and the impact of this, her needs around being fed which eventually occurred, ensuring her medication was provided on time, which was often not the case and this involved advocacy. Importantly, the social worker advocated for Jean's involvement in decision-making as at times she was not consulted and this stripped her of even more control over her life.

The social worker was involved with Jean from her entry to the facility to the time she passed away, and was one of the consistent people in her life who was able to provide support but who also kept reminding Jean and those around her about who she was, and that she was more than her Parkinson's.

This case study compilation was kindly provided by Dr Fotina Hardy and reflects her experience as a social worker working with people with Parkinson's. Case studies have been deidentified to protect people's privacy.

For further support and information see the Australian Association for Social Workers at aasw.asn.au

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