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NSW GOVERNMENT Health South Western Sydney Local Health District

How to cope with a Stranger in your lounge room?

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So what is it like for the wife of a person with an ABI?

What is it like for a person with an ABI?

Why talk about lounge rooms?

- A significant part of the multidisciplinary team support is juggling the competing needs of the individual with an ABI, their family, funding bodies, attendant care workers and their employing agencies.
- Increasing awareness of the tension that exists between it being a private home and workplace at the same time.
- Identifying strategies to prevent the breakdown of the care and support programs rather than waiting until a crises arises.

Why talk about lounge rooms *cont.*?

- Attendant Care Workers are expected to function within complex social situations without necessarily having the knowledge, skills or structured supports to do so.

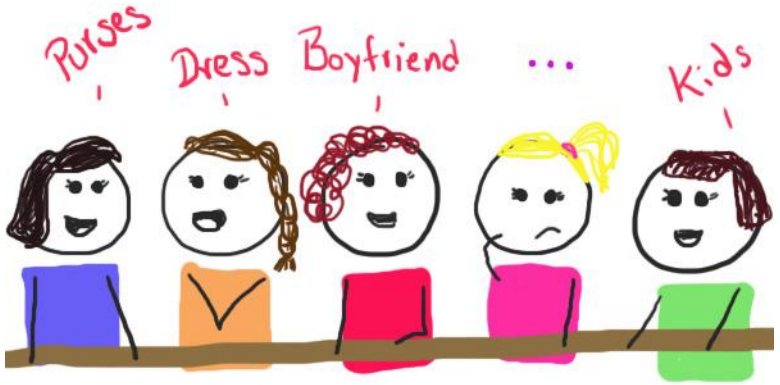
- Acknowledgement of the gaps in the system in relation to the mental health of the family members and the Attendant Care Workers following an incident resulting in tragedy.

A stranger in YOUR lounge room!

- Close your eyes
- Picture your lounge room or family room at home where you and/or your family would spend the most time
- Now picture that you are sitting there in your pyjama's and slippers, your hair is all messy, you are planning to have one of those days where you laze around the house and don't do much
- Now consider, that you know someone is about to arrive and see you in your pyjama's, See that you haven't washed up the dishes yet, see that you haven't tidied the house
- How would you feel?
- Would you feel guilty or embarrassed or judged by the state of the house?
- Would you feel like you needed to clean up before they arrive?
- Would you feel that you need to talk to them or engage in small talk with them?

What it would be like having attendant care workers in your home?

- Suddenly additional people in your home
- Sense of having personal privacy invaded
- Small talk
- Being judged
- People wanting to talk to you
- Having particular ways of doing things
- Your belongings being touched, moved, misplaced
- Disruption to your routine
- Family discussions/arguments
- Expectations



What it is like for the individual, and their carers/family members

Image from Synapse – The FACTS Book

What is important for Attendant Care Workers to understand about the psycho-social situation

- Families feeling overwhelmed
- High levels of stress
- Isolation
- Financial challenges
- Guilt/sense of obligation
- Ongoing grief and loss/Ambiguous loss

What is important for Attendant Care Workers to understand about the psycho-social situation *cont.*

- Relationship changes – sexual and emotional and practical.
- Changes in roles. What is the role of a partner vs what is the role of a ”family” carer? What happens when you don’t have your partner being able do their “role” anymore?
- Feeling that no one else understands.
- Anger/ Resentment .
- Future plans/ Fear about the future.

Some issues that arise for ACWs working in people's homes

"Is **THIS** the line you're telling me not to cross?"

- This is a workplace and a family home
- Boundaries – privacy issues, mixed messages
- Awareness of their own values
- Differences between the needs of the individual with the ABI and the needs of their families
- Understanding and addressing the families' distress/ coping
- You don't have to like the family members – they may not like all carers
- Bullying in the workplace
- Non predictable reactions by the family members i.e. loss of control, ongoing grief and loss process, changing financial pressures
- Family member needs / expectations change
- Co-dependence

So what can we do to improve the outcomes?

Successful discharge planning and ongoing interventions:

1. Training for the ACWs and their agencies
2. Education for the family members
3. Support for the individual in relation to adjustment to the changes that will occur in their home environment.
4. Ongoing lines of communication and problem solving approach to reduce the likelihood of crises.

1: Topics that are essential to address in training for ACWS

- Understanding ABI
- Disability facts
- Understanding Mental health
- ABI and MH links
- The impact of the injury on all involved – recognising MH concerns in the household
- Family roles and responsibilities, motivation for family members becoming carers
- Clarifying agencies procedures and processes including daily documentation, and the expectations of therapists in relation to documentation.
- Support structures implemented by the agencies for the ACWs, such as debriefing.

Some example training materials

- The following slides show some of the training materials used in previous educational sessions provided.

- Crossover between education to the ACWs and their agencies

(service providers) and the family members and the individual with the ABI

So what is Mental Health?

Current Classification:

- ***Mood disorders.***
- ***Anxiety disorders.***
- ***Substance-related disorders.***
- ***Psychotic disorders.***
- ***Cognitive disorders.***
- ***Developmental disorders.***
- **Personality disorders**

Role changes / delineation

- **What is the role of a partner?**
- **What is the role of a carer?**
- **What happens when you don't have your partner being able to do their "role" anymore? Their end of the bargain!**
- **Guilt – sense of obligation**
- **Retirement – spending more time together**

Good Attendant Care from an ACW perspective

- United front – despite frustration with co-workers - no conflict
- Everyone does their share and meets expectations
- No one oversteps their boundaries
- No mixed messages

ACWs can have MH issues too!

- **Burnout**
- **Compassion Fatigue**

Service Providers responsibilities to ensure a balanced workplace

- Acknowledge the balance between workplace and family home – before accepting the package to all parties involved
- Ensure the ACWs involved are aware of the issues that may be present
- Ensure that ACWs know how to report MH issues when they arise
- Acknowledge to family members that their expectations of staff may vary over time, and ensure systems are in place to address this
- Be mindful of where the family members are on the grieving continuum, and how this impacts on their expectations, and structure this into the care plan
- Be mindful of the conflict that could arise between siding with client over the family members

Ways to ensure a balanced workplace for the ACWs

- Remember the house you are entering is a workplace
- Be respectful of the workplace
- Maintain workplace etiquette – like private calls during work hours
- Be mindful of your disposition
- Take the time to define the boundary of breaks before commencing
- Eating with client – role of social communication training – still need a break
- Be mindful of complaining to the family members – are they the right person?
- United front – co-workers, organisations
- Acknowledge this is a tough job.
- The role is always evolving – living through the highs and lows of the individual and their family members.

Recognising MH in Family Members

- Evidence of change may be seen in:
  - the Environment
  - the family member themselves
  - the person with the disability

So what can you do if you recognise MH issues in family members?

- **Your role is the observer**
- **Who do you talk to?**
- **Do you raise it with the family member?**
- **Do you report it to your manager/supervisor?**
- **Do you put it in handover notes? What is an incident report?**
- **Allied health team involved – can you contact them?**

So what can you do if you recognise MH issues in family members?

- Documentation – what are you writing about the family?
- Email addresses? Are they communal?
- Unified approach – partnerships with external resources
- Support systems need to be in place
- Orientation – discussion about these presentations
- Whose responsibility?

2: What should be included in education to the family and other informal supports

- Education about the role of ACW
- Emphasising the conflict between their private home vs it now being a workplace
- Education about the individual needs and changes of the person with the ABI
- Discussion about practical aspects such as provision of food, communication styles, social expectations such as eating and breaks
- Discussion about workplace issues such as health and safety, workplace etiquette i.e. private phone calls, family crises, sharing of personal information
- Establishing processes for communication regarding issues and problems
- Discussion of expectations and flexibility

3: Support for the individual with the ABI to aid their adjustment to having people in their homes?

- Supporting them to feel they have choice and control
- Highlighting expectations, such as how meals are prepared, household tasks are completed
- Privacy
- Independence vs Dependence / Rehabilitation vs Care – what is the role of the ACW?
- Highlighting the impact on the whole family not just them
- Access to ongoing support - adjustment takes time

4: Effective Communication to limit crises

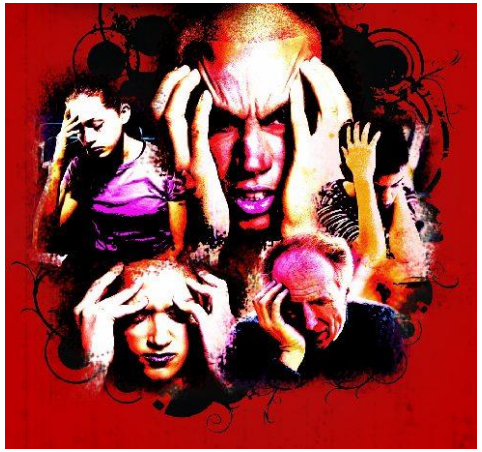
- Inclusion of ACW representation in multidisciplinary case conferences, and sharing of information such as emails regarding clinical issues

- Importance of regular opportunities for ACWs to discuss ideas, approaches and issues in relation to supporting the client, such as facilitated de-briefing by the Social Worker/Psychologist

- Regular communication between the key parties, such as the family members, the care agencies, and clinicians, and clear role delineation available for all involved

Case study - RH

- Gentleman with TBI
- Living at home with Mother – with physical injuries
- Sister with ID and MH
- Brother with substance abuse
- Client with depression and self-harm attempts
- Increased issues with client – volatile family situation increased



Case study - RH

- Disclosure to ACWs not professionals or family members about mood issues
- ACWs present with suicide attempt
- Impact on supporting the client with family member issues
- Trauma for ACWs exposed to family issues
- Workplace issue – hygiene, using facilities – impact on ACWs when reporting
- Boundary issues – family member playing ACWs

So what makes good attendant care?

Having a family-centred and collaborative approach

Is an amalgam of:

- The experience of the person receiving attendant care and what they bring.
- What the worker brings.
- How the ACWs work together with their clients.
- The experience of clients' family members and what they bring (in situations where attendant care is provided in family settings).
- What the care agency brings.
- What the case manager brings.
- What the other therapists/health professionals bring

⇨ **Therefore it is a juggling of MULTIPLE PERSPECTIVES!!**

To reduce the impact of a stranger in your lounge room

- Education and clear boundary setting prior to support commencing for:
  - The individual with the ABI
  - The family members and other non-paid carers
  - ACWs and their agencies

- Ongoing opportunities to optimise communication once support has commenced

➡**Early recognition and resolution of issues**

THANK YOU

- Any questions?
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