



Proposal to ACT Health to fund new position for
Huntington's disease focussed social worker

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Aims

- Respond to the individual needs of carers and their families with bespoke solutions
- Improve access to health, allied health and disability services
- Reduce unnecessary admitted and non-admitted ED, acute and mental health separations
- Liaise with allied health and other services to increase understanding of Huntington's disease
- Alleviate social isolation
- Raise awareness and reducing stigma

1. Social Worker for Huntington's disease (HD) families

A full-time Social Worker dedicated to HD families in the ACT would provide the coordinating point for HD families accessing services. The Social Worker's role would cover:

- a) Supporting HD families by:
- Visiting affected individuals and families to support and assist with problem solving
 - Helping liaise with health professionals and services and being part of specialist clinics
 - Interacting with government and non-government agencies for example Centrelink, Police, NDIS, justice, housing, Legal Aid etc.
 - Working with younger people at risk of HD and/or living in families with HD
 - Running support groups both for carers and for people with HD
 - Liaising as appropriate between families and health and allied health providers
 - Assisting with NDIS pre-planning
 - Long-term point of contact as circumstances evolve.

Outcomes

- More holistic engagement with family strengthens family relationships
 - Enables broader support networks to develop
 - Reduces risk of crisis outcomes such as avoidable hospitalisations, arrests by police.
- b) Training and providing information to HD health and allied health professionals, particularly in aged care or specialist disability facilities where people with HD are residents.

The Ask

Huntington's NSW & ACT seeks funding of \$161,583 (plus indexation) per annum to employ and support a social worker filling this role. Funding will cover salary, on-costs, car/travel; promotions; administrative overhead. We believe the role would save the ACT health system by reducing inappropriate / preventable hospital admissions and making current services more effective.

Annual budget

Huntington's NSW & ACT Proposed Social Worker Budget			
Item	Detail	Rate	Amount p.a.
Social worker	SCHADS Award 6/3	\$43.99	\$85,780.50
Superannuation	9.50%		\$8,149.15
On costs	5.00%		\$6,433.54
Office	Shared		\$12,000
Travel	Mileage p.w.	600	\$22,464
Communications	Phone	\$1,200	\$1,200
Communications	monthly cost	\$40	\$480
IT	Laptop + software	\$4,000	\$4,000
Admin overhead		15%	\$21,076
TOTAL			\$161,583

2. Co-ordination with the HD Service, Westmead Hospital

Many HD families in the ACT make use of the HD Service at Westmead Hospital, and the HD Service tries to accommodate ACT clients in several ways. We believe that there are mechanisms to create a more intentional relationship between the HD Service and key health professionals in ACT Health that would bring more focused expertise, including information and training, into Canberra to the benefit of both HD families and the ACT Health system. We believe that one of the senior neurologists employed by ACT Health could take a role in facilitating this outcome.

3. Improving Residential Care options

We recommend ACT Health provide an incentive for one or two Residential Aged Care facilities to specialise in caring for younger people with HD, the experience of HD residents could be vastly improved and the number of crisis hospital admissions from RAC facilities reduced.

At the same time, we recommend ACT Health work with Huntington's NSW & ACT to encourage disability providers to develop Huntington's specific accommodation using relevant NDIS funding.

Assumptions re avoidable hospitalisations

Avoidable hospitalisation type	Average unit cost ACT 16-17 ¹	Potential savings
10 non-admitted ED presentations	\$541	\$5,410
5 admitted ED presentations	\$1,052	\$5,260
5 acute separations (via ED)	\$13,010	\$65,010
5 mental health separations	\$16,676	\$83,380
Total		\$159,060

A more detailed picture of what a Huntington's social worker could achieve

By John Conaghan, Huntington's social worker, Hunter New England LHD

- Core to the social work role is the ability to develop and maintain sound working relationships with individuals and families affected by HD and act as a secure base for this client base to consult with on an ongoing basis. In addition, having a working knowledge of HD as a genetic, neurological and psychiatric disorder is imperative in helping families better understand the condition.
- Social workers are the co-ordinating force behind the service delivery to these families ensuring people are linked into proper specialist health services (namely neurology and psychiatry) with the co-operation of the general practitioner. Through this linkage, those affected and their carers obtain appropriate ongoing medical care, which helps keep people informed of the progress of their illness and receive appropriate relief of symptoms associated with HD. This specialist care also acts to keep the local general practitioner informed of the person's treatment and better able to facilitate appropriate medical care at the local level.
- Social workers provide an active educative and advocacy role on behalf of families by ensuring comprehensive informed applications are made to government agencies to make sure people receive proper income support through Centrelink, an adequate regime of care and support through the National Disability Insurance Scheme (NDIS) or if older My Aged Care and appropriate housing. Facilitating sound applications is an essential part of the advocacy process provided by social workers. Patients and their families are more often than not confused by the apparent complexity of these applications and require the input of social work to navigate people through systems which often present as disinterested and impersonal. Without the provision of this social work input people are often left feeling disenfranchised and without access to the regime of social care they require increasing the likelihood of additional pressure upon the tertiary hospital system to deal with essentially non-health related issues.
- Ensuring people have adequate medical care and treatment ensures carers are supported in their crucial role and are best able to continue providing the necessary guidance, reassurance and comfort to the affected person. When the affected person receives appropriate medical care and

¹ <https://www.ihsa.gov.au/publications/national-hospital-cost-data-collection-report-public-sector-round-21-financial-year>

treatment the chances of averting preventable hospital admissions is maximised because their care is already being managed on an outpatient basis.

- As social workers become familiar with those individuals and families affected by HD they can help build links between people for example by the provision by support groups for carers and those who have either been confirmed to carry the causative HD gene and/or those affected. By facilitating these links, carers for example can feel less isolated, able to share their experiences of care with others in a similar position and feel more able to continue their caring role minimising the chances of separation and crises in care for the affected person. Supporting families in this way also communicates to offspring of those affected that despite the debilitating nature of HD it is possible to be supported well within families who are supported well themselves lessening the burden upon adolescent mental health services. Likewise, developing links amongst people confirmed to have the causative HD gene and/or are symptomatic can also relieve their sense of isolation and separateness from community life. Knowing another person with HD has been shown to lessen the risk of depression and suicide.² Such interventions accompanied with the maintenance of adequate support from formal and informal support networks helps build resilience and adaptive responses with this much stigmatised and marginalised group.
- It is well known that those in most need of social work input are those persons who are symptomatic for HD and live alone. Living with a cognitive impairment that only becomes progressively more impaired inevitably results in this group of persons being unable to effectively plan and manage their daily life. In the absence of supportive family and friends, the social worker is often called upon to accept responsibility for driving the changes which need to occur to recalibrate the person's daily living. These changes can include making application to the Guardianship Tribunal for the appointment of an alternate decision-maker to assist with the implementation of services, accommodation and medical care and treatment, in addition to financial management (if needed). Such social work interventions not only result in improved quality of life but again prevent downstream crisis admissions to hospital and burden upon the tertiary hospital system to take on all the foundational preliminary work routinely undertaken by the social worker in the community working with these individuals.
- Notwithstanding the myriad of social work interventions, it is the nature of the worker-client relationship which is pivotal to achieving successful outcomes for the client group. It is because the social worker deals with highly charged emotional issues often in an environment with inadequate resources that it is the relationship which is so pivotal as a key resource in bringing about change.

² Lipe H, Schultz A, Bird TD (1993) Risk factors for suicide in Huntington's disease: a retrospective case controlled study. *Am J Med Genet (Neuropsychiatric Genet)* 48:231-233