

Brief to Hon Bill Shorten MP

22 September 2023



**Australian
Brain Tumour**
COLLABORATIVE

About Us

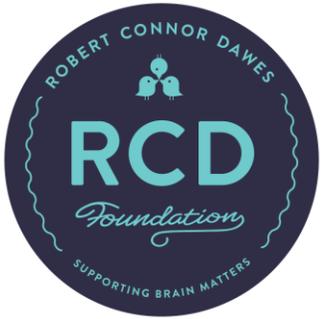
Craig Cardinal

- Chair Brain Tumour Alliance Australia
- Chair Australian Brain Tumour Collaborative

Fiona Hassmann

- Manager and Senior Advocate National Advocacy Service

The Australian Brain Tumour Collaborative



Psycho-oncology Co-operative Research Group

National Advocacy Service (NAS)

Operation and Management



Funding and Governance



National Advocacy Service (NAS)

- ▶ ***Established in November 2021 due to significant challenges faced by families attempting to access both Tier 2 & Tier 3 support services.***
- ▶ Supports brain tumour patients nationally through:
 - General information & advice (online, phone or face to face)
 - Connecting patients/families to local support services/contacts within your region
 - Applying to the NDIS, Centrelink, Carer Gateway, etc
 - Information resources such as 'The Survivorship Diary'

Situation

- ▶ Significant impact to Acquired Brain Injury (Brain Tumours) Patients, Families and support communities due to recent and widespread rejection to become Participants of the NDIS
- ▶ Until very recently, rejections were rare and appropriate NDIS supports were funded through NDIS and palliative supports coordinated through mainstream systems
- ▶ Patients and Families facing wide range of substantial hardships already

Aim

- ▶ Request immediate stop to recent and current changes to assessment approach of Acquired Brain Injury (ABI) patients accessing NDIS
- ▶ Inform Minister and Department of statistics and needs of brain tumour patients
- ▶ Inform Minister and Department of how NDIA approved ABI Participants interact with commonwealth and state/territory supports services (APTOS) for palliative and end-of-life support

About Brain Cancer

- ▶ More children die of brain cancer than any other disease
- ▶ More people under 40 die of brain cancer than any other cancer
- ▶ Disabilities are most often severe – physical, cognitive, psychosocial, functional
- ▶ Impacts are usually significant psychosocial, work life and financial toxicity
- ▶ No major changes in treatments or prognosis in 30 years
- ▶ Often family member needs to stop working and become full-time carers

About Brain Cancer cont..

- ▶ Commonly, unable to self-navigate through typical cancer survivorship journey and identify supports
- ▶ Often unable to return to work (full-time or otherwise), drive, care for self or family or function independently
- ▶ Disabilities can be from rapid degeneration or long-term impairments to death
- ▶ Most common brain cancer survival is 18 months

NAS has supported
914 patients/families
since November 2021

Count of Service_Expected

BY SERVICE, ACTIONED OUTCOME

Service	ACTIONED	NOT YET	Total
NDIS	263	10	273
POMF Retreats	133	4	137
Other	104	16	120
Financial Assistance	83		83
Carer Gateway	78	4	82
Centrelink CA	65	5	70
Counseling	52	1	53
Centrelink DSP	44	2	46
Regional Supports	21	11	32
Centrelink CP	20	4	24
HACC	21	1	22
My Aged Care	19	2	21
Centrelink Carer Payment	10	2	12
Support Groups	10	1	11
Legal Aid / Wills & POA	8	1	9
Companion Card	4	1	5
Financial Counselling	4	1	5
Centrelink AP	3	1	4
Total	943	68	1011

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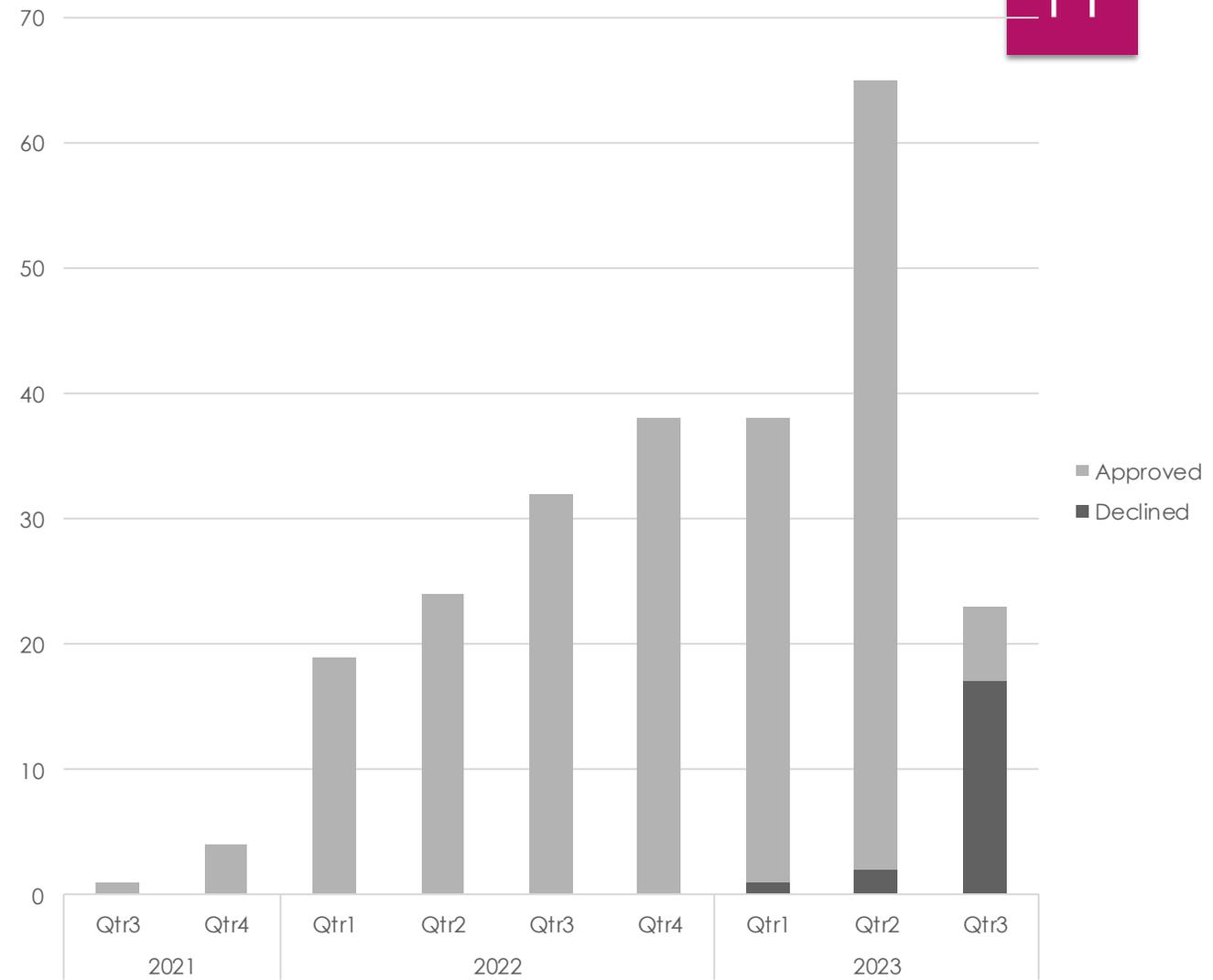


~260 patients since service initiated
(increasing demand)

Nov 21 to 2nd QTR 2023

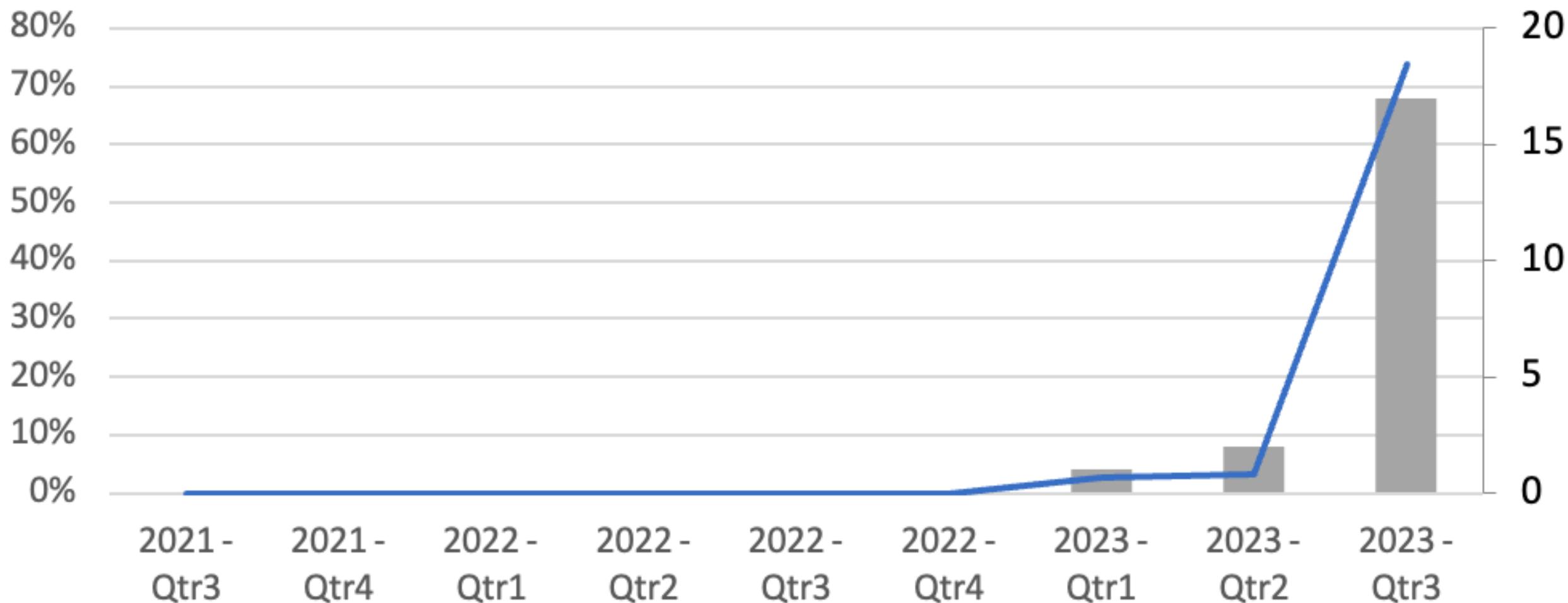
almost 100% became participants.

Recent changes almost **inverse**
causing **immediate hardships** for
brain tumour patients and families



Number and proportion of applications declined by the NDIA for people with brain tumours (National Advocacy Service data)

Chart Area



ID	Age	State	Approved	Declined	Reason	Submitted	In Progress	More Evidence Request
848	52	QLD	May-23			Mar-23		
731	57	QLD	Mar-23			Feb-23		
741	62	WA	Apr-23			Feb-23		
813	42	NSW	Apr-23			Feb-23		
762	62	QLD	Feb-23			Feb-23		
784	59	QLD	Mar-23			Feb-23		
503	56	QLD	Mar-23			Feb-23		
718	39	QLD	Mar-23			Feb-23		
281	47	QLD	Mar-23			Feb-23		
816	61	VIC	Mar-23			Feb-23		
678	16	SA	Mar-23			Feb-23		
690	46	VIC	Mar-23			Feb-23		
839	61	QLD	Mar-23			Feb-23		
694	38	QLD	Mar-23			Feb-23		
742	62	QLD	Mar-23			Jan-23		
749	27	NSW	Feb-23			Jan-23		
370	77	NSW	Feb-23			Jan-23		
451	59	QLD	Feb-23			Jan-23		
677	57	QLD	Feb-23			Jan-23		
545	49	QLD	Feb-23			Jan-23		
695	64	VIC	Jan-23			Jan-23		
722	54	ACT	Jan-23			Jan-23		
414	52	VIC	Feb-23			Jan-23		
744	56	VIC	Feb-23			Jan-23		
466	36	SA	Feb-23			Jan-23		
452	48	VIC	Jan-23			Dec-22		
679	65	VIC	Jan-23			Dec-22		
284	42	VIC	Feb-23			Dec-22		
328	43	ACT	Dec-22			Dec-22		
339	41	VIC	Jan-23			Dec-22		
457	37	QLD	Jan-23			Dec-22		
665	54	NSW	Jan-23			Dec-22		
673	62	SA	Jan-23			Dec-22		
407	59	SA	Jan-23			Dec-22		
661	60	NSW	Jan-23			Dec-22		
662	50	NSW	Jan-23			Dec-22		
373	43	VIC	Jan-23			Dec-22		
446	56	QLD	Jan-23			Dec-22		

ID	Age	State	Approved	Declined	Reason	Submitted	In Progress	More Evidence Request
446	56	QLD	Jan-23			Dec-22		
698	34	VIC	Jan-23			Dec-22		
412	34	QLD	Jan-23			Dec-22		
659	65	QLD	Jan-23			Dec-22		
669	48	NSW	Dec-22			Nov-22		
645	59	SA	Jan-23			Nov-22		
534	57	QLD	Dec-22			Nov-22		
357	62	SA	Jan-23			Nov-22		
340	40	QLD	Feb-23			Nov-22		
386	29	VIC	Dec-22			Nov-22		
424	61	QLD	Dec-22			Nov-22		
422	62	QLD	Dec-22			Nov-22		
336	33	NSW	Dec-22			Nov-22		
498	58	VIC	Dec-22			Nov-22		
720	58	NSW	Dec-22			Nov-22		
542	64	QLD	Dec-22			Nov-22		
383	41	VIC	Dec-22			Nov-22		
409	56	QLD	Dec-22			Nov-22		
441	37	VIC	Feb-23			Oct-22		
477	28	VIC	Nov-22			Oct-22		
390	43	VIC	Oct-22			Oct-22		
381	44	VIC	Nov-22			Oct-22		
461	65	QLD	Nov-22			Oct-22		
449	42	QLD	Nov-22			Oct-22		
450	65	ACT	Nov-22			Oct-22		
219	51	VIC	Nov-22			Oct-22		
394	57	QLD	Sep-22			Sep-22		
352	63	NSW	Sep-22			Sep-22		
420	25	NSW	Oct-22			Sep-22		
421	51	QLD	Oct-22			Sep-22		
391	62	QLD	Oct-22			Sep-22		
206	33	VIC	Oct-22			Sep-22		
348	50	VIC	Sep-22			Sep-22		
243	44	QLD	Oct-22			Sep-22		
442	55	QLD	Oct-22			Sep-22		
368	34	QLD	Oct-22			Sep-22		
380	60	ACT	Oct-22			Sep-22		
404	39	NSW	Oct-22			Sep-22		
456	45	QLD	Apr-23			Jan-23		

ID	Age	State	Approved	Declined	Reason	Submitted	In Progress	More Evidence Request
700	63	SA	Aug-23			Jun-23		
938	31	NSW	Jul-23			Jun-23		
945	45	NSW	Aug-23			Jun-23		
388	52	VIC	Jul-23			Jun-23		
788	7	NSW	Jul-23			Jun-23		
824	33	VIC	Jul-23			Jun-23		
1015	56	VIC	Aug-23			Jun-23		
1062	55	VIC	Aug-23			Jun-23		
1022	60	QLD	Jul-23			Jun-23		
902	40	ACT	Jul-23			Jun-23		
1033	61	QLD	Aug-23			Jun-23		
980	57	SA	Jul-23			Jun-23		
908	57	QLD	Jul-23			Jun-23		
431	59	NSW	Jul-23			Jun-23		
963	49	ACT	Jun-23			Jun-23		
763	41	VIC	Jul-23			Jun-23		
697	59	QLD	Aug-23			Jun-23		
797	34	VIC	Jul-23			Jun-23		
976	60	QLD	Jun-23			Jun-23		
808	57	QLD	Jul-23			Jun-23		
1011	59	ACT	Jul-23			Jun-23		
845	9	VIC	Aug-23			May-23		
931	61	QLD	Jun-23			May-23		
478	40	VIC	Jul-23			May-23		
1084	56	VIC		X	524.1 h	May-23		Rejected
910	51	VIC		X	534 f	May-23		Rejected
1002	47	QLD	Jun-23			May-23		
907	57	QLD	Jun-23			May-23		
935	57	QLD	Jul-23			May-23		
990	54	QLD	Jun-23			May-23		
750	14	NSW	Jul-23			May-23		
951	48	NSW	Jun-23			May-23		
929	58	VIC	May-23			May-23		
993	33	QLD	Jun-23			May-23		
670	46	VIC	Jun-23			May-23		
779	40	QLD	Jun-23			May-23		
954	40	QLD	Jun-23			May-23		
900	39	VIC	Jun-23			May-23		

ID	Age	State	Approved	Declined	Reason	Submitted	In Progress	More Evidence Request
404	39	NSW	Oct-22			Sep-22		
456	55	QLD	Sep-22			Sep-22		
420	50	VIC	Oct-22			Sep-22		
341	54	ACT	Oct-22			Aug-22		
276	36	NSW	Sep-22			Aug-22		
277	40	NSW	Sep-22			Aug-22		
376	46	QLD	Sep-22			Aug-22		
303	54	VIC	Sep-22			Aug-22		
375	46	QLD	Sep-22			Aug-22		
280	61	QLD	Aug-22			Jul-22		
379	44	SA	Aug-22			Jul-22		
369	48	QLD	Oct-22			Jul-22		
228	55	QLD	Aug-22			Jul-22		
372	49	QLD	Sep-22			Jul-22		
393	49	QLD	Aug-22			Jul-22		
275	62	VIC	Aug-22			Jul-22		
349	61	VIC	Aug-22			Jul-22		
305	53	VIC	Mar-22			Jul-22		
374	48	VIC	Aug-22			Jul-22		
355	57	SA	Aug-22			Jul-22		
344	44	NSW	Aug-22			Jul-22		
354	58	QLD	Jul-22			Jun-22		
351	57	ACT	Jul-22			Jun-22		
362	40	QLD	Jul-22			Jun-22		
312	51	NSW	Sep-22			Jun-22		
366	53	QLD	Jul-22			Jun-22		
286	44	QLD	Jul-22			Jun-22		
377	57	QLD	Jul-22			Jun-22		
214	31	NSW	Jul-22			Jun-22		
365	28	QLD	Jul-22			Jun-22		
197	60	VIC	Jun-22			May-22		
252	50	VIC	May-22			May-22		
223	58	NSW	Jun-22			May-22		
345	46	QLD	Jun-22			May-22		
301	65	NSW	Jun-22			May-22		
297	53	VIC	Jun-22			May-22		
289	50	QLD	Jun-22			May-22		
250	62	QLD	Apr-22			Apr-22		

ID	Age	State	Approved	Declined	Reason	Submitted	In Progress	More Evidence Request
250	62	QLD	Apr-22			Apr-22		
249	45	QLD	Apr-22			Apr-22		
248	43	NSW	May-22			Apr-22		
315	54	NSW	May-22			Apr-22		
271	64	VIC	May-22			Apr-22		
218	9	VIC	May-22			Apr-22		
830	12	QLD	Apr-22			Apr-22		
332	61	VIC	May-22			Apr-22		
268	57	VIC	Apr-22			Mar-22		
264	51	VIC	Apr-22			Mar-22		
205	64	VIC	Apr-22			Mar-22		
241	63	ACT	Mar-22			Mar-22		
319	47	QLD	Mar-22			Feb-22		
278	54	QLD	Mar-22			Feb-22		
191	52	VIC	Mar-22			Feb-22		
304	50	NSW	Mar-22			Feb-22		
236	62	VIC	Mar-22			Feb-22		
302	38	QLD	Apr-22			Feb-22		
216	46	VIC	Mar-22			Feb-22		
232	65	VIC	Mar-22			Feb-22		
254	59	QLD	Mar-22			Feb-22		
310	37	QLD	Mar-22			Feb-22		
286	44	QLD	Jun-22			Jan-22		
213	57	NSW	Feb-22			Jan-22		
224	39	WA	Feb-22			Jan-22		
231	66	SA	Feb-22			Jan-22		
242	58	QLD	Feb-22			Jan-22		
225	38	NSW	Feb-22			Jan-22		
229	34	VIC	Jan-22			Dec-21		
207	56	SA	Jan-22			Dec-21		
217	49	QLD	Jan-22			Dec-21		
209	37	NSW	Jan-22			Nov-21		
364	40	VIC	Sep-22			Aug-21		

ID	Age	State	Approved	Declined	Reason	Submitted	In Progress	More Evidence Request
337	63	NSW	Jun-23			May-23		
748	54	VIC	Jun-23			May-23		
960	38	QLD	Jun-23			May-23		
798	62	ACT	Jun-23			May-23		
913	33	VIC	May-23			Apr-23		
878	50	VIC	May-23			Apr-23		

ID	Age	State	Approved	Declined	Reason	Submitted	In Progress	More Evidence Requested	Notes
1130	44	VIC		11/9/2023	S24 1 e	Aug-23			Rejected - deemed not whole of life
1127	59	VIC		12/9/2023	S24 1 e & 25 3	Aug-23			Rejected - deemed whole of life, and ineligibility for early intervention (palliative)
273	55	NSW	12/9/2023			Aug-23			Planning Meeting scheduled for next week
1082	65	QLD		X	unknown	Aug-23			Rejected - phone call to client, advised does not meet significant disability
745	25	QLD		X	S24 1 c	Aug-23			Rejected - insufficient evidence of significant reduction in physical capacity
879	52	VIC		X		Aug-23	X		More information - prognosis, treatment, progression of disease
945	45	NSW		X	S34 F	Aug-23			Rejected - most appropriately funded by another service
1035	59	NSW		X	S24 1 b	Aug-23			Rejected - insufficient evidence to indicate permanency
886	56	QLD				Aug-23	X		
1047	64	VIC		15/9/2023	S 24 1 e	Aug-23			Rejected - deemed whole of life
995	47	QLD				Aug-23	X	X	More information - prognosis, treatment, progression of disease
1019	61	QLD		11/9/2023	TBC	Aug-23			Family contacted, no details given - advised 'letter in the mail' not yet received
1137	58	NSW		17/8/2023		Aug-23	X	X	More information - prognosis, treatment, progression of disease
1012	59	VIC		12/9/2023	S34 f	Aug-23			Rejected - deemed pallative (Verbal call to family, no formal letter as yet)
948	56	VIC				Aug-23	X	X	More information - prognosis, treatment, progression of disease
1073	51	QLD				Aug-23			Passed away - still awaiting NDIS outcome
801	45	QLD		X	S24 1 c	Jul-23			Rejected - insufficient evidence of significant reduction in physical capacity
1218	5	SA		X	S34 1 f	Jul-23			Rejected -most appropriately funded by another service
982	41	QLD		X	s24 1 c	Jul-23			Rejected - insufficient evidence of reduced capacity
1105	40	QLD		X	S24 1 c	Jul-23			Rejected - insufficient evidence of reduced capacity
1036	38	NSW		X	s34	Jul-23			Rejected - deemed not whole of life, most appropriately funded by another service
1051	47	QLD		X	S24 1 b	Jul-23			Rejected - insufficient evidence of reduced capacity
686	38	VIC		X	S24 1 c	Jul-23			Rejected - insufficient evidence of significant reduction in physical capacity
701	48	VIC		X	S24 1 c	Jul-23			Rejected - insufficient evidence of significant reduction in physical capacity
950	49	NSW	Aug-23			Jul-23			
1014	59	QLD	Jul-23			Jul-23			
1010	32	NSW	Jul-23			Jul-23			
967	37	QLD			S24	Jul-23			Review underway, following rejection
1055	56	ACT	Aug-23			Jul-23			
736	55	VIC				Jul-23	X		
1083	38	QLD	Aug-23			Jul-23			
1049	63	WA				Jul-23	X		
969	46	SA	Aug-23			Jun-23			
785	10	NSW	Aug-23			Jun-23			
952	40	VIC	Jul-23			Jun-23			
700	63	SA	Aug-23			Jun-23			

NDIS Rule 7.4

Health (excluding mental health)

7.4 **the NDIS will be responsible for** supports related to a person's ongoing functional impairment and that enable the person to undertake activities of daily living, including maintenance supports delivered or supervised by clinically trained or qualified health practitioners where these are directly related to a functional impairment and integrally linked to the care and support a person requires to live in the community and participate in education and employment.

NDIS Rule 7.5

7.5 the NDIS will not be responsible for:

- (A) the diagnosis and clinical treatment of health conditions, including ongoing or chronic health conditions; or
- (b) other activities that aim to improve the health status of Australians, including general practitioner services, medical specialist services, dental care, nursing, allied health services (including acute and post-acute services), preventive health, care in public and private hospitals and pharmaceuticals or other universal entitlements; or
- (C) funding time-limited, goal-oriented services and therapies:
 - (i) where the predominant purpose is treatment directly related to the person's health status; or
 - (ii) provided after a recent medical or surgical event, with the aim of improving the person's functional status, including rehabilitation or post-acute care; or
- (D) palliative care.

The Applied Principles and Tables of Support to Determine Responsibilities NDIS and other service (APTOS)

Reasonable and necessary NDIS supports for eligible people

- ▶ *'- In relation to palliative care, functional supports as part of an NDIS participant's plan may continue to be provided at the same time as palliative care services, recognising that supports may need to be adjusted in scope or frequency as a result of the need to align with the core palliative care being delivered through sub-acute health services.'*

Other Parties

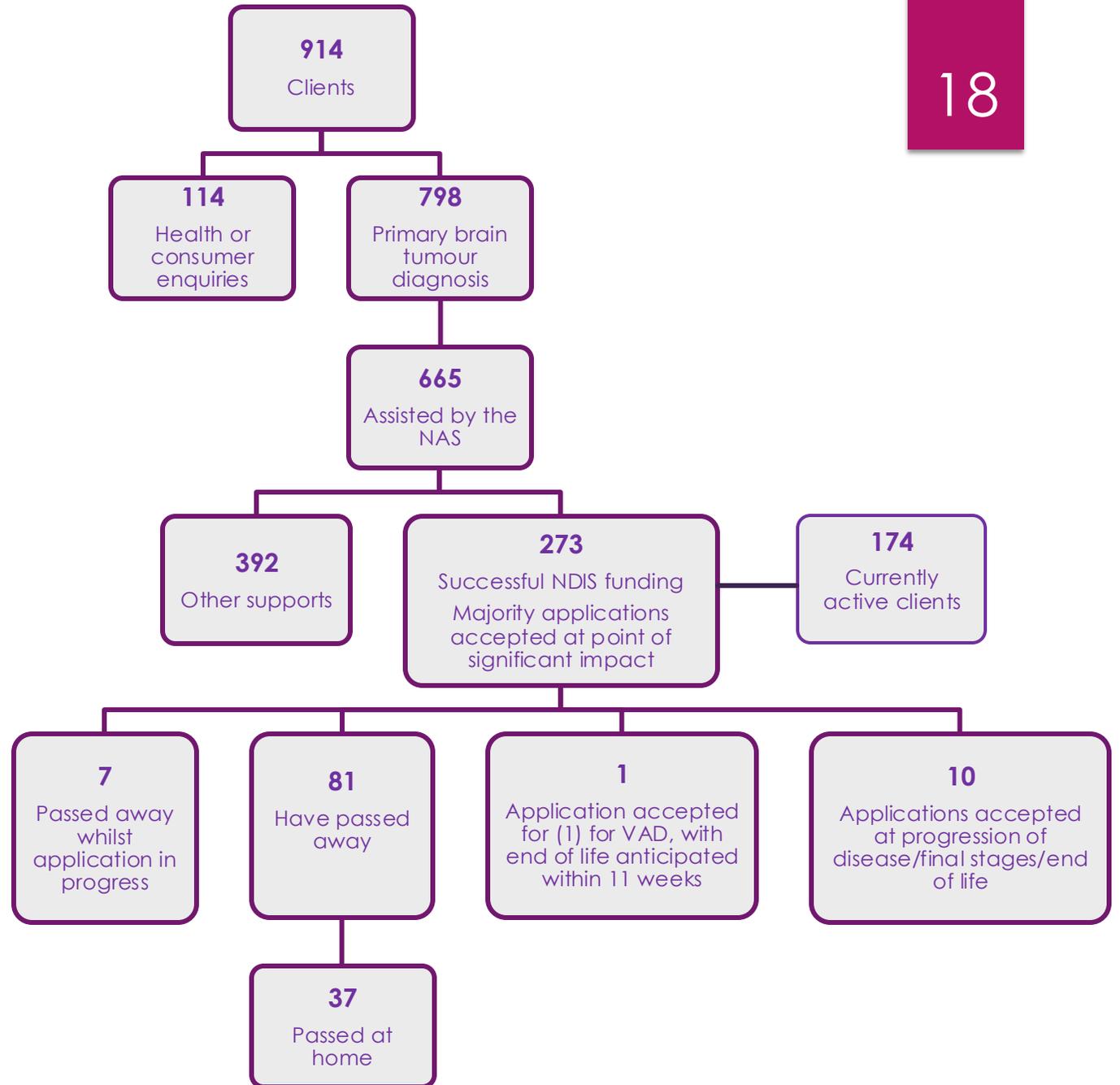
- ▶ *'-Sub-acute services (palliative care, geriatric evaluation and management and psychogeriatric care) including in-patient and out-patient services delivered in the person's home or clinical settings.'*

N.B. This is the understanding and observation of how the system was working previously for brain tumour patients requiring palliative care. And, **WORKING WELL** for brain tumour patients receiving palliative care.

NAS has supported 914 patients/families since November 2021

Reason for initial referral

- Patient/Carer request counselling
- Patient/Carer request financial assistance
- Patient looking for Centrelink assistance
- Patient/Carer looking for access to Retreats
- Patient/Carer seeking community/local services
- Hospital services requesting counselling, community services or financial grants for patients
- Hospital services seeking presentations on services



Typical NDIS Supports

CORE SUPPORTS	CAPACITY BUILDING	CAPITAL
<p>Personal Care – prompting and assistance whilst showering, dressing</p> <p>Daily Living – socialise, assist in the home, company at home, provide independence, assist with cooking, encourage walks in the garden & daily routine etc</p> <p>Community Access – assistance to with transport to hospital or social engagements and support to attend. Encourage independent social access to community</p> <p>Home & Yard Maintenance</p> <p>Consumable Budget</p> <p>Respite</p>	<p>Occupational Therapy - For assessment on functional capacity, prescription of appropriate equipment, assistance with daily living strategies</p> <p>Speech Therapy- For strategies maintaining language due to Asphasia</p> <p>Physiotherapy- To encourage movement and maintenance of physical capacity</p> <p>Psychology - To strategise, and feel more equipped to enter social and everyday public environments</p>	<p>Funding for mid-cost equipment or rental budget for same.</p>
<p>PLAN MANAGEMENT</p>	<p>SUPPORT CO-ORDINATION</p>	<p>TRANSPORT PERIODICAL PAYMENT</p>

Typical Health Supports

HOSPITAL	GP	PALLIATIVE (Home Setting)
<ul style="list-style-type: none"> • Team of Specialists for Surgery/Treatment (Neurology, Neurosurgery, Oncology) • Diagnosis • Rehabilitation if deemed for improved outcome • MRI imaging for monitoring • Admission for medical needs • Prescribing of medication • Refer to palliative care, when appropriate 	<ul style="list-style-type: none"> • Community symptom management • Prescribing of medications • Communications to medical team • Additional diagnosis of related side effects • Management of related side effects • Refer to Palliative Care, when appropriate 	<ul style="list-style-type: none"> • Triage patient on receipt of referral • Allocate to assessment team, to determine needs • Complete routine check in with patient • Social Worker, Allied Health Team for home safety check & symptom management • Nurse & Clinician for pain/symptom increase • 24/7 Nurse at end of life stage • Provide & maintain subcut/driver for medications • Provide 'life extinct' evaluation post passing • Discharge from routine supports, if disease considered stable (not end of life) in most cases

COMMUNITY/GOVERNMENT (not limited to)

Carer Gateway * State/Local Government Support Schemes * Companion Card * Disability Parking * Religious Groups providing supports *
Not for Profit Foundations providing supports

PALLIATIVE CARE (inpatient):

All supports are completed by Health in entirety

NDIS Participant Transition to Palliative care and End of Life

- ▶ All Participant's disabilities need to be permanent (life-long/whole of life) as part of meeting access requirements.
- ▶ Irrespective of the disability – all Participants who don't die by accident will require palliative care/end-of-life support and will die with the disability.

Brain Tumour applicants are currently being assessed as automatically palliative only/end-of-life and require mainstream supports only. Completely opposite to APTOS. And, highly stressing and challenging for patients and families.

Case #1

Low Grade Tumour

Community/State/Charity supports

NO NDIS funding

47yo Male from Victoria

Diagnosed March 2023

Summary:

Requires NDIS access

Non end of life

Currently supported through Tier 2 means



- ▶ **Impact:** Unable to work, drive, personality changes/aggression, socially withdrawn, lack of problem-solving capacity, short term memory loss, increased cognitive fatigue, cannot independently travel (public or other)
- ▶ **Social:** Wife works – home alone. Is reliant on friends/family for supports
- ▶ **Domestic:** Is slower in all movements, is reliant on wife for all household supports. Regularly overwhelmed which can increase his aggression.
- ▶ **Finances:** Reduced to single income, reliant on savings, unable to access super
- ▶ **Non-NDIS:** Community Transport, Carer Gateway, Centrelink Carer Allowance, Companion Card, Counselling via Charity Foundation, Survivorship Diary, Communications to Health Team.
- ▶ **NDIS Access:** Not deemed significant disability at this time. Early in diagnosis, waiting for further impact to present before considering for access.

Case #2

Low Grade Tumour - High Grade
Community/State/Charity Supports
NDIS funded

64yo Female from Queensland
Glioma diagnosed – 2013
Glioblastoma diagnosed – 2020

Summary:

Passed: May 2023

following 12 months of supports from both
NDIS & Queensland Health.



- ▶ **Impact:** unable to work since 2013, unable to drive due to seizure history, socially withdrawn, easily confused, language loss, short term memory loss, cognitive fatigue – increased to: need for full time carer, disability equipment, community support by carer, bladder incontinence, medication supervision, support in all area's of daily life (meal prep, house-keeping, bill paying)
- ▶ **Social:** has had years of increased sense of burden, reliance on others, restricted independence and minimised social circle, increased need for equipment creating difficult leaving home
- ▶ **Domestic:** increased reliance on husband over years, at time of new diagnosis is restricted to front yard of home only as cannot safely access rear of property due to stairs
- ▶ **Finances:** able to release superannuation in 2020, and is living off these funds in addition to DSP.
- ▶ **Supports provided:** Centrelink Carer Payment, Carer Allowance, Carer Gateway Companion Card, Psychology via Griffith Uni Trial, Survivorship Diary, Disability Parking Permit, Peace of Mind Foundation Retreat, Communications to Health Team, NDIS, Community Palliative Care
- ▶ **NDIS Access:** applied for and achieved in June 2022 (no earlier rejections)
- ▶ **NDIS Supports:** support worker for home and community access, regular STA (away from home), assist with meal preparation and home crafts, increased exercise and mobility by physio and OT input, social access to shops routinely, appropriate equipment for safety
- ▶ **Palliative Care Support:** social worker for mental wellbeing, occupational therapist for home safety assessment, allied health assistance for symptom monitoring, telehealth to clinician/nursing team, weekly in-home nurse for management, leading to 24/7 on-call nurse towards end of life.
- ▶ **NDIS End of Life Support:** support workers to continue home domestic, personal care, bedding changes and repositioning, incontinence aides, equipment rental, occupational therapy assessment

Case #3

High Grade Tumour

Glioblastoma – short prognosis

NDIS funded

45yo Male from Queensland

Diagnosed 2019

Summary:

Passed: June 2023

following 33 months with Palliative Care

& 26 months of NDIS supports

- ▶ **Prognosis:** 9mths due to inoperable, unable to tolerate standard of care treatment
- ▶ **Impact:** unable to work, unable to drive due to seizure activity, easily confused, language loss, short term memory loss, cognitive fatigue, right side weakness, blurred vision, tendency for aggression.
- ▶ **Social:** reliant on friends and family for all social access, limited to short periods of time due to cognitive fatigue. Becomes overwhelmed easily. Reliant on full time carer.
- ▶ **Domestic:** Reliant on wife for all domestic and yard maintenance. Is able to make a small snack, but reliant on wife and family for all meals. Finds this frustrating and becomes aggressive.
- ▶ **Finances:** able to access super, no insurances, limited savings, reliant on pension payments
- ▶ **Supports provided:** Centrelink Disability Pension, Centrelink Carer Payment, Centrelink Carer Allowance, Carer Gateway, Companion Card, Disability Parking Permit, Community Palliative Care, NDIS , Communications to Health Team
- ▶ **NDIS Access:** applied for and achieved in March 2020 (no earlier rejections) – 14mths post diagnosis
- ▶ **NDIS Supports:** support worker for home and community access, assist with work in the garden and home, increased exercise and mobility by physio and OT input, social access to shops and visiting friends routinely, appropriate equipment for safety, OT assessments for mid cost AT (scooter).
- ▶ **Palliative Care Support:** engaged in 2019, initially stand alone service and then worked side by side with NDIS supports. Social worker for mental wellbeing, occupational therapist for home safety assessment, allied health assistance for symptom monitoring, telehealth to clinician/nursing team, weekly in-home nurse for management, leading to 24/7 on-call nurse towards end of life.
- ▶ **NDIS End of Life Support:** support workers to continue home domestic, personal care, bedding changes and repositioning, incontinence aides, equipment rental, occupational therapy assessment



Examples of Impact from recent rejections #1

64 yo Male - GBM – New South Wales

- ▶ **Lodgement:** Considered stable disease medically. Increased cognitive decline and mobility worsening. Now using wheelie walker. Is reliant on his sisters to provide all care needs in the home setting, both have needed to move in with him. One sister is 81 years old and lives in the house, the other is 70 years old and is living in a caravan on-site. Our service-initiated Carer Gateway services and Centrelink assistance and commenced evidence gathering for NDIS submission.
- ▶ **Rejected:** Life Limiting diagnosis, best suited to Palliative Care/Mainstream supports
- ▶ **Appeal:** pending
- ▶ **Impact:** Sisters are too old to continue providing care, John has falls that mean they can't lift him safely. There are limited supports in the community setting and none are consistent. John is not yet eligible for Palliative services and therefore they will continue to struggle in the home setting.
- ▶ **IMPACT:** Patient will likely need to be admitted to long-stay in hospital or enter Aged Care for support.

Examples of Impact from recent rejections #2

25 yo Female – GBM4 - Queensland

- ▶ **Lodgement:** Considered stable in disease medically. Two applications have been lodged for this client both signed in heavy layers of evidence from Assoc. Professor Mark Pinkham. She is cared for by her sister and family. She has had to move out of her own home and is no longer able to live independently. She is seizure/falls risk in the home/community. She cannot work or drive. Have assisted with Centrelink application
- ▶ **Rejected:** family advised by phone, formal letter yet to be provided. Indicated insufficient evidence of disability.
- ▶ **Appeal:** pending
- ▶ **Impact:** Sister has young children of her own, who are now compromised in their own family life and after school activities. The home surrounds the care of the 25yo diagnosed sister in all respects. The pressure that is building in the family is not sustainable.
- ▶ **IMPACT :** Patient will need to be admitted to Respite/Long Stay in hospital or enter Aged Care for supports but likely not until family are completely exhausted and have no further options available.

Examples of Impact from recent rejections #3

45 yo Male – GBM4 - Queensland

- ▶ **Lodgement:** he is stable in disease at the time of the first lodgement in March 2023. This was rejected on the grounds of insufficient evidence of impairment and inability to indicate significant need of support. Family are disappointed and do not want to appeal, as found the process too demoralising. Alternative supports via Carer Gateway are put in place but are time limited.

In May 2023 he had increased in his deficits, and they decide to lodge a new application. At this time, there had been regrowth to his tumour and therefore medically he was also declining. He was not considered end of life by his medical team at the time of lodgement.

- ▶ **Rejected:** patient deemed palliative, end of life.
- ▶ **Appeal:** pending lodgement
- ▶ **IMPACT:** he would have benefited from supports when the lodgement was made in March, the family are now doing their best to manage him at home independently.

Large quantity of examples of current impact statements/concerns

Responses within a very short time (2 days)



Excerpts of current impact statements/concerns

John Hunter Hospital, NSW:

Albina has been hospitalised since February 2023, and medically stable for discharge since April.

Her team here at John Hunter hospital had assisted with Albina's application for NDIS support a planning meeting was held, in which we were told, Albina would not be receiving any support, only Support Coordination because of Albina's cancer diagnosis, and subsequent poor prognosis.

As such, Albina remains in hospital with no clear path for discharge, as supports funded by the Health system remain insufficient to meet the ongoing needs of Albina's disability

Austin Health, VIC:

People we refer to NDIS are young, have a notable significant and permanent disability, will deteriorate over time, but often LIVE with this condition for a number of years, despite a brain cancer GBM diagnosis.

5 rejections of ARF and access denied (4 of these patients have ABIs as a result of tumours that are considered benign or low-grade i.e. low term survival and extended prognosis)

Cabrini Health, VIC:

It is true Brain Tumours can be life limiting. This does not always mean short term.

People living with both low and the highest-grade tumours often live for long periods and this is sometimes an experience with complex disability

It is not appropriate to reject a person from accessing the NDIS on the assumption health services can fill the gap.

We don't have health services in Australia that are funded to attend to these needs. This would also be inappropriate as disability support is very different to Health Care provision.

Excerpts of current impact statements/concerns

Monash Health, VIC:

Four (4) patients between May 2023 - September 2023 have been diagnosed with a GBM and poor prognosis and 100% dependant of full time care and extensive equipment to maintain their quality of life

One (1) out of the four (4) patients is an existing NDIS participant, but unable to access additional care and support following the GBM diagnosis. Three (3) of the four (4) patients were access met for an ABI, however only able to access Support Coordination once the patients reached the planning phase.

All four (4) patients remained in hospital as a long-stay patient and/or frequently represented to the acute hospital. Average length of stay for these patients is 2- 4 months in an acute hospital bed

The Alfred, VIC:

Having to deliver a prognosis that devastates every aspect of these patients life is one thing.

Then to now have to let these patients know the option of living a life of autonomy and control is not available to them

[previously] we have seen the effect that access to NDIS has for patients and the life changing support they receive.

Canberra Hospital, ACT

*....patients who have been rejected, these patients **do not** meet the criteria for aged care due to their young age, and are requiring physical assistance with activities of daily living*

In Canberra there is currently no publicly funded home care for patients under 65 (community options have currently suspended all referrals due to no funding and regardless they are only able to provide care for 8 weeks)

one of these patients is currently in hospital, has been in for +75 days, unable to be discharged

.....Having no support means these families are being traumatised not only by their diagnosis but by the way they must live the rest of their lives without support.

Current Status

- ▶ All current rejections are being prepared to submit for **internal review**
 - ▶ ~**20** brain tumour patients
 - ▶ Number is growing
- ▶ 1 being prepared **AAT**
- ▶ Some being prepared for **Ministerial and Media attention**

Disparity in Policies

- ▶ DSS List 1 & List 2 require little evidence to receive access to DSP for Grade 3 or Grade 4 brain tumour
 - ▶ deemed Manifest for the purposes of evidence and access
- ▶ Not reflected on NDIS List A or List B
 - ▶ **Despite NDIS Guideline:**
 - ▶ ***'When do we make priority eligibility decisions:' (2-5 days)***
 - ▶ ***'Rapid deterioration in functional capacity of a person with one of the following permanent disabilities:'***
 - ▶ ***'Brain Cancer'***

IMPACT: This disparity in policy for brain cancer not being formally listed on List A or List B means by the time patients/families get access they have already struggled and now need to navigate mainstream services at the same time.

This disparity and not being formally reflected on NDIS List A or List B is core to the current issue.

Distress caused by NDIS access inconsistencies/recent rejections for brain tumour patients

34

- ▶ Despite the unannounced, immoral, poorly defined and probably illegal changes in assessment for the brain tumour communities, the NDIS seemed to be internally confused about their policy.
- ▶ Same disease, types and levels of permanent disabilities – virtually same evidence:
 - ▶ **Most rejected – Few provided access??**
 - ▶ Extremely distressing for all those rejected

NDIS overriding/disagree with specialists' advice

- ▶ **NDIS access and assessments are continually overriding treating specialists' advice**
 - ▶ Treating specialists advise palliative care not required and not end of life
 - ▶ **NDIA advise internal assessment team assess as end of life and palliative against specialist reports**

IMPACT: Treating specialists' advice being disregarded causes confusion (anger and angst) for medical profession and extreme distress for patients and families.

N.B. Independent Assessment concepts were previously discounted by political parties and the process to implement ceased. This current approach as part of determining access is far more inaccurate and damaging

Summary

- ▶ **Why has the NDIA/NDIS changed its policy without announcements or any engagement with some of the most vulnerable communities?**
 - ▶ **The awareness of the changes are being felt nationally across multiple support communities**
 - ▶ **The sweeping impact to patients, families and support communities is very significant**