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PROCEDURES-2023-2024

ADVOCACY SERVICE

Background

Since 1953, Diabetes Victoria has been a leading independent charity where the needs of people with diabetes is at the core of what we do. We value and respect the lived experience of those with diabetes.

In 2001, Diabetes Victoria appointed its inaugural Advocacy Coordinator. The purpose of our advocacy service remains improving the social and emotional health outcomes for people with a lived experience of diabetes. Diabetes Victoria's advocacy service is positioned within the Program and Services team and reports to the Head of this team. The service responds to advocacy requests internally from teams across the organisation including our NDSS (National Diabetes Services Scheme) Diabetes Helpline, Health Professional teams, Access & Equity team, Community Engagement team, peer support group members, Membership team, other staff, and volunteers.

Today our advocacy service is led by a social worker, (Advocacy Coordinator) and Advocacy Officers (Counsellor) and (Credentialled diabetes nurse educator) working in a multi-disciplinary team of health professionals.

This year 1,423 contacts were received by our advocacy service, per cent of those contacts were from people with type 1 diabetes, while the remaining 11 per cent came from people with type 2 diabetes.

At present Diabetes Victoria is the sole organisation with an advocacy service dedicated to those with diabetes, their family members and health professionals. The aim of this services is to lessen the social and emotional health impacts of diabetes. Our team value the lived experience of people with diabetes and their needs are the core of what we do. This service is available at no cost to Diabetes Victoria Members and non-members.

People with diabetes, educators, social workers and other allied health professionals from hospital and community settings, endocrinologists, and members from our peer support groups came directly to Diabetes Victoria with problems as well as suggestions on how to improve service provision, policy, and quality of life.

This document is intended to aid, with internal discussions and future planning for diabetes' advocacy and presents the:

- aims of Diabetes Victoria's advocacy service
- guiding principles
- referral sources
- rating scale of seriousness
- daily procedures involved in responding to a request for advocacy help
- outline of the information collected at each contact
- steps often involved in problem solving
- procedures in place to maintain privacy and confidentiality for the individual
- role, responsibilities, and statement of limitations for the Diabetes Victoria's Advocacy Coordinator and Advocacy Officers
- costs

- internal and external reporting mechanisms.

Other documents aiding this forward planning with reflection on 21 years of offering individual advocacy include:

- A model of diabetes advocacy in action at Diabetes Australia Vic Jan 2011
- Diabetes Victoria's Annual Advocacy Report
- Diabetes Victoria's Advocacy Coordinator and Advocacy Officer's Position Descriptions
- Diabetes Victoria's Annual Advocacy Staff Work plans
- Diabetes Victoria's Monthly advocacy reports.

All reports listed above are accessible on the Diabetes Vic website and for internal staff via SharePoint.

Rationale for Diabetes Victoria's advocacy service

Case example – diabetes related discrimination and stigma in the workplace Mark is a 30-year-old who had been working in the retail supermarket industry for four years. During this time, he had progressed to an assistant store manager role. At a recent performance review, it was documented that he was in line for a promotion as well as participation in a prestigious training program. All this changed two months ago when he was diagnosed with type 1 diabetes. At the time when he contacted Diabetes Victoria's advocacy service, he was ready to leave the job and go on Centrelink unemployment benefits (New Start Allowance/ Job Seeker). He felt bullied, unsupported, angry, and alone. When he asked about the promotion and training course, he was told that someone who had just joined the company would take on that role now that he was sick with 'the diabetes.'

Over the eight weeks Mark:

- received information about specialist disability employment services
- secured no cost legal help via his Union
- read information about discrimination on the website of the Victorian Equal Opportunity and Human Rights Commission (VEOHRC)
- lodged a formal complaint of discrimination with VEOHRC
- reconnected with his diabetes educator close to his home
- connected with Money help's financial counsellors
- talked with his GP about accessing a Medicare funded clinical psychologist to help him over this rough patch in his life
- had his Union delegate represent him at meetings with his former employer
- read the NDSS /ACBRD information sheets on mental health and seeking psychological services
- thought about joining a peer support group with an interest in physical activity i.e., Hypoactive
- read Diabetes Victoria's booklets on diabetes in the workplace
- enrolled to attend NDSS Oz DANFNE programs and Carbsmart
- received information about the private practice diabetes clinic and Diabetes Vic
- Was able to let off steam at any time during this process with our advocacy staff.

Mark now knows his rights. His claim for discrimination with VEOHRC was accepted and a conciliation meeting took place. He is now employed full time elsewhere.

As a member of Diabetes Victoria, Mark came directly to us for help with this workplace stigma and discrimination problems. He could have gone to the Disability Discrimination Legal Centre for legal advice and case management, or the Victorian Equal Opportunity and Human Rights Commission to lodge a complaint but he did not know about these organisations. Expecting we would help; he came to us, and the connection was made to the range of services based on our team's expertise in diabetes and community resources.

Diabetes Victoria's advocacy service works alongside people with diabetes when they:

- face stigma and discrimination, while at work and other areas of public life
- need help to secure their rights

- want help to say what they want to say
- request help to link to the services that they need
- expect action to improve diabetes services and policies.

Aims of Diabetes Victoria's advocacy service

Our advocacy service aims to:

- Encourage all people with diabetes to be aware of their rights and responsibilities (empowerment and proactive advocacy)
- build on people's strengths and problem-solving skills so they can tackle their most important current issues (empowerment reactive advocacy)
- ensure that all people with diabetes have access to affordable and timely diabetes management, care, and emotional health services (systemic and proactive advocacy)
- help resolve instances of diabetes stigma and discrimination in public life experienced by people with diabetes (reactive and systemic advocacy)
- reduce/lessen the emotional, social, and financial impacts of living with diabetes (proactive, systemic, and reactive advocacy)
- assist people with diabetes and their family members to self-advocate where possible (empowerment and reactive advocacy)
- establish supportive environments for optimum health outcomes, while addressing gaps in services. For example, extending opportunities for peer support, and developing collaborations to effect policy and legislative change where needed (systemic and proactive advocacy).

Guiding principles

The principles that guide our advocacy include:

- Confidentiality- (except where life is in danger) of information obtained and adherence to maintaining privacy of all records that may identify a person. Case records are kept in Sales force (Diabetes Victoria's organisation wide data collection system) and placed in confidential storage off site for seven years
- self - determination of the individual with diabetes and direction in all decisions and actions
- responding to all requests in a timely, respectful, and professional manner
- offering all clients confirmation of discussions in writing. For example, email and/or letter usually within 2-3 business days
- advising all service users that records are kept of all advocacy contacts, and that they alone have access to these records. Information acquired during contacts is not passed on to a third party without prior written consent
- respecting language, cultural differences and needs
- adhering to our organisation's health literacy guidelines
- when requests are outside our scope of practice, referring people on to other services.

Sources of referral to Diabetes Victoria's advocacy service

People with diabetes came directly to our advocacy service. Referrals also came from the NDSS Helpline plus staff across our organisations. Health professionals external to Diabetes Victoria and family members, carers, or friends of people with diabetes also seek out our service. Referrals are accepted by letter, telephone, in person, virtually, email and via our website. The most frequent referral method was by email followed by telephone and a message left on the Diabetes Victoria website. Other methods that those with diabetes heard about our service included:

- reading an advocacy article in our membership magazines; Circle magazine
- community presentations by advocacy staff

- recommendation from their GP, diabetes educator, social worker, or endocrinologist
- return users of this service.

Currently Diabetes Victoria does not advertise or promote this service. In 30 per cent of cases, people with diabetes have recontacted the service when another problem has arisen.

Assessing the impact of the problem on the person with diabetes

What is important and urgent for one person with diabetes may not be the same for another. Gauging and assessing the impact of a presenting problem for an individual occurs with every contact with this service. This “seriousness rating” - is dependent upon the impact of the problem on the person with diabetes. The Advocacy Coordinator and Advocacy Officers allocate an initial rating based on the information presented by the person. These ratings are revised while contacts as current information emerges. Ratings are helpful in assigning priorities, time, and resources to resolve matters to the satisfaction of the person. In most instances those contacting the service are responded to within 48 hours.

For example, in the above-mentioned case study, Mark made initial contact with Diabetes Victoria via our website after hours (4 am) and his email requested contact as soon as possible. On hearing his voice which was one of distress, despair, and anger, he requested a face-to-face meeting that afternoon to tell his story and show paperwork from his employer. A virtual meeting was arranged at with DV advocacy staff. From that first point of contact and for the following five contacts, Mark was assigned a ‘high’ seriousness rating as the impact of this matter on his financial status, mental health, physical health, and personal relationships was substantial. Subsequent contacts over eight weeks saw the rating steady at ‘medium’ until these matters were resolved to his satisfaction. To date we have not had any further contacts from him, and an offer to recontact as needed remains open.

The seriousness/ impact rating explained:

1. **high ratings** involved problems where changes in practice are needed to avoid a reoccurrence for individuals or groups of those with diabetes. At times of high ratings there may also be a need for policy development and immediate referral to relevant external expertise including the following types of situations:
 - if life is in danger, a person mentions wanting to end their life or another person's and has a plan
 - an urgent need to access insulin and/or funds to purchase diabetes medicines and supplies
 - in cases of family violence
 - in cases of child neglect requiring reporting to child protection services
 - severe depression, psychological distress including diabetes related distress including the parents of young people attending early childhood and schools
 - requests from diabetes health professionals to discuss a complex case and make suggestions
 - child custody matters where a child has type 1 diabetes and the parents are in dispute and distress about access matters
 - a loss of income
 - the need for urgent accommodation
 - unfair dismissal from a paid job
 - access to services for vulnerable groups. For example, those with multiple chronic and complex health conditions, live in areas that are socio-economically disadvantaged, are in prison, are homeless, reside in nursing homes, refugees or asylum seekers or international students not eligible for any Australian Government financial help
 - direct workplace discrimination
 - loss and or suspension of a driver's license
 - possible unethical and/or unlawful conduct by service providers and/or health professionals.

2. **Medium ratings** involve the following:

- disputes with service providers
- difficulties accessing health services
- problems in accessing diabetes supplies
- gaps in information
- instances of stigma and discrimination in public life i.e., recreation
- requests for help with appeals processes with Government service providers (Local, State and Federal) as well as community services
- discourtesy, disrespect, and differences of opinion with a service provider
- difficulty accessing affordable insurances including -life, income protection and travel
- breaches of client confidentiality of medical information
- suggestions for improvements to diabetes services from people with diabetes, their family members and health professionals.
- requests for help from carers/family members concerned about a family member living with diabetes and not coping

3. **Low ratings** are assigned to advocacy contacts where a single telephone call or letter is required to resolve the problem or request. For example, a NDSS information sheet.

Over the last 22 years 50-55 percent of all contacts had a medium to low seriousness rating with the remaining 40-45 percent of contacts having a high seriousness rating. The remainder were low rating. For additional information on the problems presented and the outcomes for those with diabetes, refer to previous Diabetes Victoria's Annual Advocacy Reports. Our team's reports are freely available on the Diabetes Victoria website.

The response procedure described

At all times, those with diabetes and health professionals can leave messages on our voice mail service, email or make contact via our website. Individuals can request a virtual, COVID safe face-to-face meeting online and in some cases site and home visits have been arranged. Any in person contact is dependent on COVID- 19 public health instructions from Victoria's Chief Medical Officer.

During the first contact an assessment is made after providing the opportunity for the person to tell their story of concern, problem, or suggestion for a service improvement. Usually by the end of an initial discussion, the person decides about the course of action and the timeline to complete the request is made by mutual agreement. All who use this service are offered written confirmation of the discussion, decisions, and actions. In 99 percent of cases this offer is accepted.

Most often requests are responded to within one- two workdays. Although with working remotely across COVID- 19 contact times may be extended. While on annual leave, current advocacy clients are advised in advance and the email/phone number for an alternative contact are given.

All advocacy contacts are recorded in Diabetes Victoria's Salesforce data base. During COVID-19 no hard copy case files are used, and all records are electronic. These records form the basis of monthly and annual advocacy reports to the Program and Services Team Manager.

Contact information collected

At each contact, the following data is collected:

- a description of the presenting concern
- name and contact details (with permission)
- type of diabetes
- place of residence and/or postal address
- email address (with permission)
- source of the referral and/or how you heard about this service
- Diabetes Victoria's membership status
- language spoken
- if the person identifies as Aboriginal or Torres Strait Islander
- date of first contact and all subsequent contacts
- decisions made
- actions taken.

Problem solving steps

The Advocacy Coordinator and Officers undertake the following problem-solving steps:

- identify the presenting problem(s) with the person and make an assessment as to whether this is a matter that Diabetes Victoria can help with and/or refer to another organisation as well as assignment of a seriousness rating
- think through the problem(s) and confer with colleagues as needed
- examine the impact of the problem(s)
- work towards an understanding of the relevant facts
- achieve some mutually agreed clarity
- with the relevant parties, identify thoughts and actions to resolve and or lessen the impact of the problem. This includes determining if a response is required at a local, state and/or national level
- identify other resources that can help
- routinely include mental/emotional health information and where to get help
- document decisions made as well as actions taken, by who and when
- review actions and refer to community organisations and other health professionals where possible
- engage in professional self-reflection and peer review with an eye to improving service delivery and additional professional learnings needed

Problems are resolved by mutual agreement with the offer to recontact later if required.

For more detailed information about the role of our model of diabetes advocacy, refer to "A model of diabetes advocacy in action," January 2011.

Diabetes Victoria's Advocacy Coordinator and Officers actively encourage people with diabetes to self-advocate, while supporting them in the making of informed choices/decisions and/or actions. This is achieved through strategies such as:

- helping individuals to define, clarify and prioritise problems as well as identifying workable solutions
- undertaking research
- assisting with linkage to services and resources in a timely manner
- helping with the drafting of correspondence
- where appropriate, attending meetings or consultations with the person as an independent third party
- developing professional networks.

Privacy and confidentiality

Routinely the Advocacy Coordinator and Officers inform individuals:

- that notes will be taken, kept for 7 years and remain confidential to a third party
- the content of the discussion and any decisions made can be confirmed in writing
- of the Advocacy Coordinator's and Officer's name and direct contact details.

Individuals are also given the option to remain anonymous and not provide any personally identifying information. Case records and personally identifying information continues to be handled in accordance with privacy policies, principles, and procedures. (Refer to Diabetes Victoria's Privacy Policy)

For the last 22 years, 95 percent plus of individuals have accepted the option to receive a letter that sets out discussion points, decisions made, action to be taken and services and resources used.

The Advocacy Coordinator and Officers

The Advocacy Coordinator and Officers are employees of Diabetes Victoria and are persons who have broad experience in both advocacy and counselling.

A designated number of consecutive hours per week are allocated to action individual advocacy requests and projects by the Advocacy staff.

The Advocacy Coordinator and Officers are located within the Programs and Services team at Diabetes Victoria. The Advocacy Coordinator is responsible for managing advocacy requests and concerns and reports directly to the Manager of the Program and Services team.

Costs to those requesting advocacy help

Advocacy services are provided at no cost to the individual with diabetes, their family members and health professionals. Where individuals with diabetes are encouraged to become members of Diabetes Victoria and where appropriate a membership brochure accompanies any correspondence

Responsibilities of the Advocacy Coordinator and Officers

Diabetes Victoria's Advocacy Coordinator and Officers are responsible for local and state matters of concern and work with other Diabetes Australia State and Territory advocacy staff on National matters.

Monthly and annual advocacy reports monitor trends, including an assessment of gaps in services for vulnerable groups of people with diabetes and recommendations are made.

Responsibilities, duties, and tasks undertaken across any year appear in the position descriptions and work plans. (Refer to Appendices 1 and 2)

Statement of limitations

Diabetes Victoria's advocacy staff are not professional pleaders or barristers and are not authorised to act in this manner.

Diabetes Victoria's annual risk management reviews continued to include our individual advocacy service. Potential risks are identified, and plans are put in place to avoid risks while undertaking this activity.

Occasionally, a problem or issue arises where, despite all efforts, a resolution is not reached. At this time if actions sought are not agreed to, Diabetes Victoria reserves the right to withdraw its individual advocacy service after consultation with the individual.

Reporting mechanism

The Advocacy Coordinator and Officers provide monthly written reports and an annual advocacy report to the Board of Diabetes Victoria.