

Helping with Haemochromatosis

**A review of support and information available for people with
Haemochromatosis.**

Developed for Haemochromatosis Australia.

June - October 2016

This project was undertaken by Social Work student, Selka Beyerle, studying at the University of Tasmania, as part of the practicum component of her course.

This report is not intended as an academic article. It is intended as an internal review of resources offered by Haemochromatosis Australia.

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Executive Summary

The “Helping Haemochromatosis” project sought feedback from people with a diagnosis of haemochromatosis (Hh) and their support people, about their experiences of diagnosis and access to support and information. In addition, the project considers the impact of health literacy issues on the ability of people to access, understand and act on health information.

The project identified that people continue to encounter challenges on their pathway to diagnosis and that key messages about Haemochromatosis are still not properly understood by many people in the community. Finding simple ways of conveying key messages about Haemochromatosis symptoms, its hereditary nature, diagnosis and treatment remain important in building awareness.

Participants identified engagement with a range of different types of information, with both print and online information being identified as important. Peer support and sharing of stories, experiences and knowledge were important sources of support for some, while the latest research articles were important to others. Being aware of individual preferences and abilities, and promoting the availability of different sources of information, is important in ensuring people have access to relevant information.

Identifying new ways of capturing people’s attention with creative awareness campaigns and simple, accessible information remains an ongoing challenge for future activities aimed at building awareness.

Purpose and Scope of the Project

The purpose of this report was to review the support and information available to people with a diagnosis of haemochromatosis (Hh), their family, friends and support people.

The main aims of the project were:

- To review information and support currently provided by Haemochromatosis Australia (HA).
- To identify alternative support and information that has been helpful to people.
- To consider ways of increasing awareness of haemochromatosis in the broader community.

Method

In the first phase of the project, people in southern Tasmania with Haemochromatosis were invited to attend an evening meeting. Through facilitation of this meeting, participants were invited to share their experiences of being diagnosed and the types of support and information that had been helpful to them on their journey.

Several people made contact who were unable to attend the meeting. Therefore, the second phase of the project involved meeting individually with people and conducting casual interviews based on the meeting outline.

The third phase of the project involved administering an online survey, seeking feedback from people about their experiences of accessing support and information.

In addition, a literature review was conducted, considering the impact of health literacy levels on the ability of people to access and understand health related information and support. Using a health literacy lens to consider the content and presentation of current HA resources, some recommendations were collated for future consideration.

Results and Discussion

Focus Group and Interviews

An invitation to attend a discussion around Haemochromatosis support and information was distributed to members via email. The event was also promoted through the HA Website and Facebook page. In addition, flyers were distributed through the Hobart Blood Bank and Royal Hobart Hospital. A notice was put on 2 community online noticeboards and flyers pinned on local Linc noticeboards.

The meeting was attended by 8 people, including 6 with a diagnosis of haemochromatosis and two support people who had also been impacted by the condition. Due to time restrictions, and the flow of the meeting, the full agenda for discussion was unable to be met. However, the experiences, thoughts and ideas generated, were useful in identifying some common themes. Please see Appendix A for an original breakdown of intended areas for discussion.

Five people made contact who were unable to attend the group meeting and agreed to participate in individual interviews instead. Two were interviewed in person, one by phone and two others provided feedback via email. These interviews followed the general format of the meeting outline.

From information and experiences gained from the group meeting and interviews, key themes are identified below.

Diagnosis

- Most participants were diagnosed some time ago, prior to the development of HA's current range of resources.
- At the time of diagnosis, participants wanted to learn as much as they could about the condition.
- Some were happy with general, basic information, others were interested in academic articles and information.
- Finding a GP/health professionals that understood the condition was important in participants feeling supported and as though they were able to manage their condition.
- Lack of knowledge/understanding by health professionals and delayed or misdiagnosis was a common frustration.
- Support from family and friends were important in navigating challenging pathways to diagnosis.
- A known family history supported early diagnosis for several participants.

Post Diagnosis Support

- Following diagnosis, attending information sessions was identified as useful in better understanding the condition and feeling supported.
- Online support groups and social media sites were identified as being very important areas of ongoing support for some participants.
- Two participants suggested simplifying the wording in the brochure, booklet and family letter to make them more accessible to people.
- Participants identified that individual's stories in the member newsletter were of ongoing interest.
- Participants indicated overall that they were happy with information on the website, though some felt they had only belatedly been made aware of its existence.

Awareness

- Participants felt there is increasing awareness of haemochromatosis in the community.
- Overall, participants expressed there was a need to further promote and raise awareness of Haemochromatosis to ensure early diagnosis and limit harm.
- Participants indicated they regularly take opportunities to spread awareness of Haemochromatosis in their daily life when opportunities arise.
- Suggestions for awareness raising included; more TV commercials, presence on social media and identifying a famous/well known identity with Haemochromatosis who would be willing to help promote the cause.
- Better GP education and awareness was also raised as an important issue.

It is worth noting that vast majority of participants were diagnosed several years ago prior to development of the current resources provided by HA. As many participants had already gathered information from other sources and were comfortable with their treatment, their experiences of accessing current versions of HA resources and their current support needs would be quite different to experiences of people who have only recently been diagnosed and are accessing HA resources for the first time.

In addition, there was speculation about whether improved awareness of Haemochromatosis in the community had resulted in smoother pathways to diagnosis for people being diagnosed more recently, or whether the same issues were being experienced.

Therefore, a survey was developed to help gain some insight into experiences from a broader spectrum of people in the community.

Online Survey

An online survey was developed with the use of Survey Monkey, seeking information about the types of information and support that has been most useful to people. Participants were also asked about their experiences of diagnosis and suggestions on raising awareness of Haemochromatosis in the broader community.

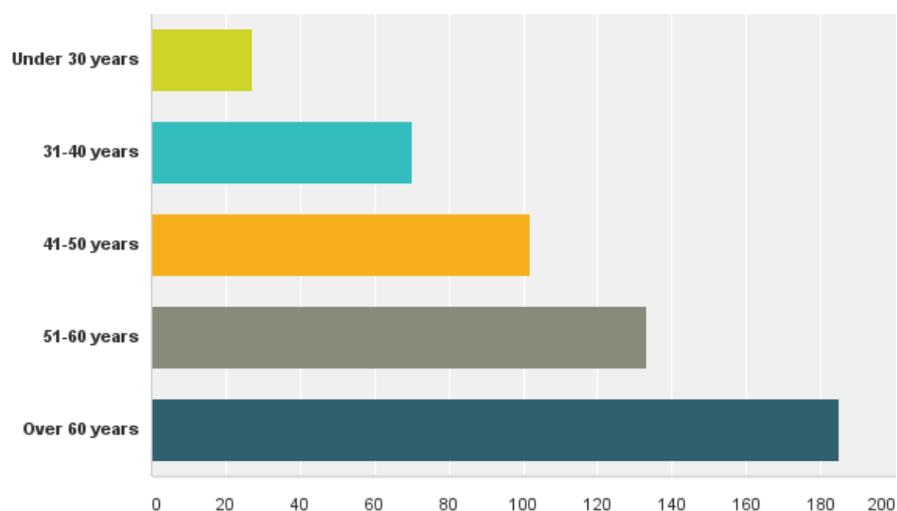
The survey was open for 3 weeks and promoted through HA's website, Facebook page and emails to members of HA and contacts gained through other phases of this project. In addition, flyers were distributed through Red Cross Blood Bank in Hobart.

A total of 520 people participated in the survey. Of this group, 468 participants reported having a diagnosis of Haemochromatosis, while 52 participants did not. While there is the potential for a variety of statistical analysis from this data, limitations in time and resources for this project have limited the ability for complex analysis. In addition, graphs generated by Survey Monkey displayed inconsistent presentation at times with the program not allowing some simple changes. Again, time limitations for this project did not allow generation of graphs in alternative programs. Basic analysis of results are discussed below. The data will remain available for HA's use in further analysis if considered to be of future use.

Age

Question 1 asked participants to identify their age. 517 participants answered this question. The graph below provides a summary of participant age groups.

Graph 1: Age of Participants



Pathways to Diagnosis

Participants in the focus group and interviews had all been diagnosed some time ago. Prior to the survey, there was some speculation about whether awareness of Haemochromatosis had increased and whether those people newly diagnosed had experienced a smoother pathway to diagnosis.

Question 4 asked people to rate their pathway to diagnosis on a scale of 1 – 5, where 1 was simple and straightforward and 5 was long and very complex.

Graph 2: Ratings of Pathway to Diagnosis

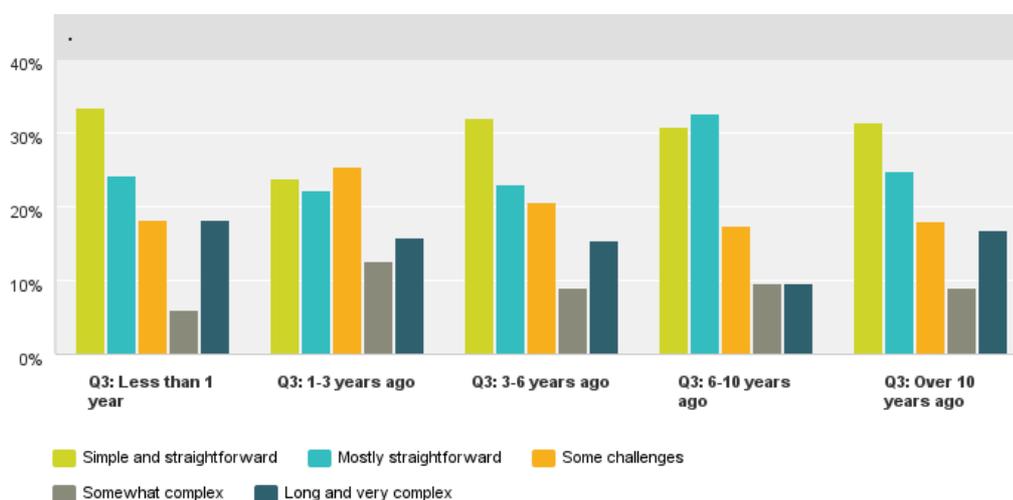


Table 1: Summary of Ratings for Pathway to Diagnosis

	Simple and straightforward	Mostly straightforward	Some challenges	Somewhat complex	Long and very complex	Total
Q3: Less than 1 year	33.33% 11	24.24% 8	18.18% 6	6.06% 2	18.18% 6	10.48% 33
Q3: 1-3 years ago	23.81% 15	22.22% 14	25.40% 16	12.70% 8	15.87% 10	20.00% 63
Q3: 3-6 years ago	32.05% 25	23.08% 18	20.51% 16	8.97% 7	15.38% 12	24.76% 78
Q3: 6-10 years ago	30.77% 16	32.69% 17	17.31% 9	9.62% 5	9.62% 5	16.51% 52
Q3: Over 10 years ago	31.46% 28	24.72% 22	17.98% 16	8.99% 8	16.85% 15	28.25% 89

The results show that the spread of ratings of the complexity of diagnosis have remained fairly similar across all groups, whether diagnosed recently or some time ago.

- The average rating for people diagnosed fell between 2 (mostly straightforward) and 3 (some challenges).
- The percentage of people experiencing complex pathways to diagnosis remained very similar whether diagnosed recently or some time ago.
 - An average of 24.45% of people across all groups, rated their pathway to diagnosis as somewhat complex or long and very complex.
 - On average, 25.72% of people diagnosed within the last 6 years rated their diagnosis as complex or very complex.
 - On average, 22.54% of people diagnosed over 6 years ago rated their diagnosis as complex or very complex.
- The percentage of people experiencing a simple or mostly straightforward diagnosis remained fairly stable, regardless of when diagnosed, with an average of 55.67%

These results suggest there has been little overall change in the complexity of people’s pathway to diagnosis over time.

Question 5 asked participants to indicate what led to their diagnosis. The purpose of this question was to again see how people’s pathways to diagnosis may have changed over the years. Gaining information about the most common pathways to diagnosis may also help to guide areas for future support, education and awareness raising activities.

Graph 3: Factors Contributing to Diagnosis

(Note: Vertical axis indicates actual number of people (not %). Limitations of Survey Monkey will not allow graph to show percentages for this particular data. Time and resource limitations for this project did not allow for development of graph in alternative program.)

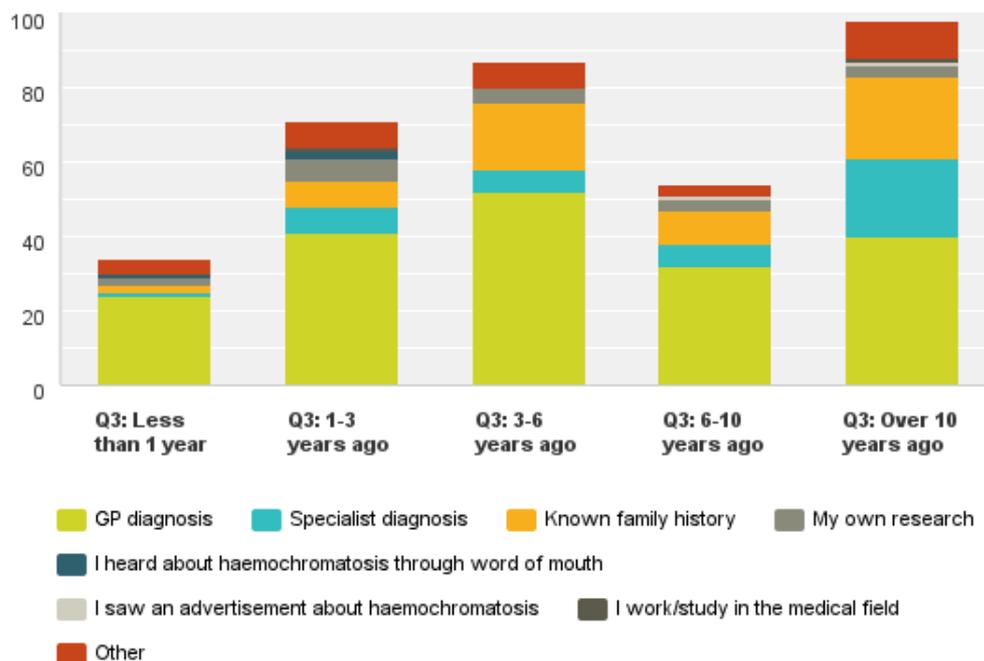


Table 2: Data showing factors contributing to diagnosis

	GP diagnosis	Specialist	Known Family History	Own Research	Word of Mouth	Advertisement	Work/ Study	Other	Total
Less than 1yr ago	72.73% 24	3.03% 1	6.06% 2	6.06% 2	3.03% 1	0%	0%	12.12% 4	10.83% 34
1-3 years ago	66.13% 41	11.29% 7	11.29% 7	9.68% 6	3.32% 2	0%	1.16% 1	11.29% 7	22.61% 71
3-6 yrs ago	66.67% 52	7.69% 6	23.08% 18	5.13% 4	0%	0%	0%	8.97% 7	27.71% 87
6-10yrs ago	60.38% 32	11.32% 6	16.98% 9	5.66% 3	0%	1.89% 1	0%	5.66% 3	17.2% 54
Over 10yrs ago	45.45% 40	23.86% 21	25% 22	3.41% 3	0%	1.14% 1	1.14% 1	11.36% 10	31.21% 98
Total Respondents	189	41	58	18	3	2	2	31	314

There were some notable trends indicating a changing method of diagnosis for people diagnosed recently, compared with those diagnosed some time ago.

- There was a notable increase in the percentage of people being diagnosed by their GP.
 - 45.45% of people diagnosed over 10yrs ago were diagnosed by their GP.
 - 66.67% of people diagnosed 3-6yrs ago were diagnosed by their GP.
 - 72.73% of people diagnosed in the last year were diagnosed by their GP.
- In addition, the percentage of people diagnosed by a specialist appeared to notably reduce among those people diagnosed more recently
 - 23.86% of people diagnosed over 10 years ago were diagnosed by a specialist.
 - 7.69 % of people diagnosed in the last 3-6yrs were diagnosed by a specialist.
 - 3.03% of people diagnosed in the last year were diagnosed by a specialist.

These results could suggest that there may be increasing awareness among GP's, rather than relying on referrals to specialists for diagnosis/treatment. A number of participants shared positive experiences of relationships with GPs and Haemochromatosis being picked up through routine blood tests.

“Routine blood tests showed raised ferritin which caused dr to ask about haemochromatosis history.”

“GP ordered iron study due to my reported tiredness”

Of the 130 participants who commented on this question, 55 (42%) reported initial contact with health professionals who were aware of Haemochromatosis or made diagnosis quickly through routine blood tests.

However, numerous people also shared negative experiences and observations, suggesting many GP's are still not fully aware or educated around diagnosis and treatment of Haemochromatosis. Of the 130 participants who commented on this question, 45 (34%) reported challenges with health professionals' lack of awareness or understanding of Haemochromatosis.

One participant diagnosed within the last year commented,

"After raised SF levels for well over a year, the GP thought nothing to worry about. I asked about the possibility of haemochromatosis and he told me 'females can't have it'."

Other examples include;

"GP was not able to interpret gene test results correctly." (Diagnosed 1-3yrs ago)

"My GP diagnosed me with an eating disorder because my most visible symptom was extreme weight loss." (Diagnosed 1-3yrs ago)

"I lived through a brain anerysm, heart attack with stent, before I was diagnosed, and around the same time had emergency surgery so I didn't lose my stomach." (Diagnosed 3-6yrs ago)

"I had five different diagnoses over the years, and had the usual run around to specialists. My condition was eventually diagnosed by a 60 year old GP trained at the University of the Pubjab,..." (Diagnosed 3-6yrs ago)

These results confirm a need for ongoing education and awareness raising among health professionals to ensure timely diagnosis and limit suffering and ill effects of iron overload.

It should also be noted that only 18.41% of respondents indicated that a known family history contributed to their diagnosis. Given the hereditary nature of this condition, more work may need to be done in promoting the importance of sharing information with family members and encouraging them to be tested for Haemochromatosis.

Question 11 asked participants to rate different types of support in order of importance. Results are summarised below.

Graph 4: Importance of Types of Support Accessed.

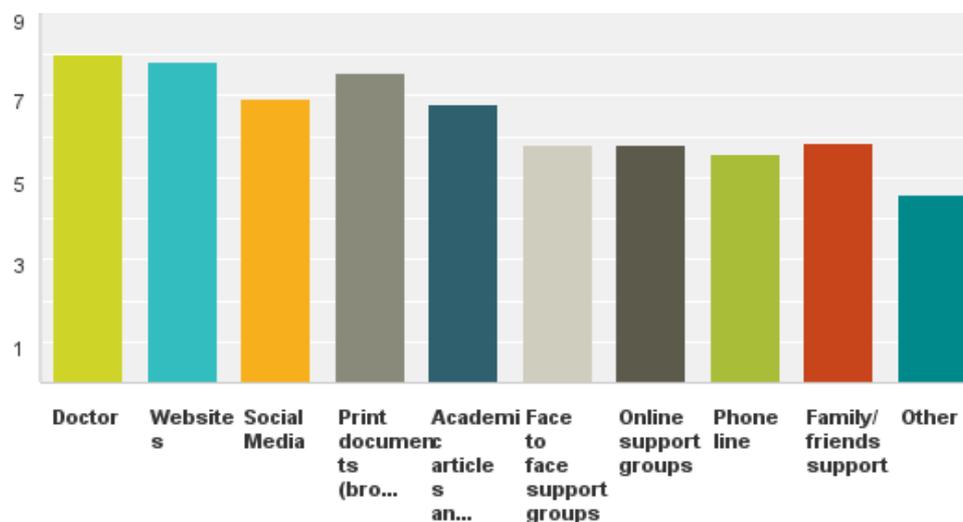


Table 3: Ratings of Importance of Different Supports

	1	2	3	4	5	6	7	8	9	10	N/A	Total	Score
Doctor	43.98% 117	11.65% 31	10.53% 28	5.26% 14	5.26% 14	3.01% 8	3.76% 10	2.26% 6	1.88% 5	5.26% 14	7.14% 19	266	8.00
Websites	17.65% 45	28.63% 73	16.08% 41	7.06% 18	7.45% 19	1.57% 4	2.35% 6	2.35% 6	3.53% 9	1.18% 3	12.16% 31	255	7.85
Social Media	6.70% 15	11.61% 26	9.82% 22	14.73% 33	6.25% 14	4.46% 10	4.46% 10	3.57% 8	3.13% 7	0.00% 0	35.27% 79	224	6.92
Print documents (brochures, booklets, fact sheets)	14.01% 36	17.51% 45	15.95% 41	11.67% 30	8.56% 22	3.11% 8	3.50% 9	3.50% 9	1.17% 3	0.78% 2	20.23% 52	257	7.54
Academic articles and research about Haemochromatosis	6.17% 15	11.93% 29	12.76% 31	16.46% 40	8.23% 20	6.58% 16	5.76% 14	3.70% 9	1.65% 4	1.23% 3	25.51% 62	243	6.81
Face to face support groups	3.06% 7	3.06% 7	2.62% 6	4.80% 11	6.55% 15	3.93% 9	2.18% 5	5.68% 13	2.62% 6	0.44% 1	65.07% 149	229	5.81
Online support groups	2.19% 5	3.51% 8	5.26% 12	7.02% 16	8.33% 19	8.33% 19	4.39% 10	3.07% 7	4.39% 10	0.44% 1	53.07% 121	228	5.80
Phone line	2.13% 5	2.55% 6	5.96% 14	5.53% 13	4.26% 10	6.38% 15	6.38% 15	3.40% 8	2.98% 7	2.13% 5	58.30% 137	235	5.56
Family/friends support	2.09% 5	6.69% 16	10.04% 24	7.11% 17	10.88% 26	12.97% 31	9.21% 22	5.44% 13	4.18% 10	0.00% 0	31.38% 75	239	5.87
Other	3.70% 8	1.39% 3	2.78% 6	3.70% 8	3.24% 7	4.17% 9	3.70% 8	5.56% 12	5.56% 12	6.94% 15	59.26% 128	216	4.60

Perhaps unsurprisingly, the results show that doctors are identified as the most important source of support. Websites and print documents are identified as the next most important sources of support, with social media and academic articles coming in just behind.

Review of HA Resources

Question 6 asked people to rate how helpful they found the current range of printed resources provided by Haemochromatosis Australia. 311 participants responded to this question and on average, participants rated these resources very positively.

Graph 5: Average Ratings of HA Print Resources
(1=very helpful, 5=very unhelpful)

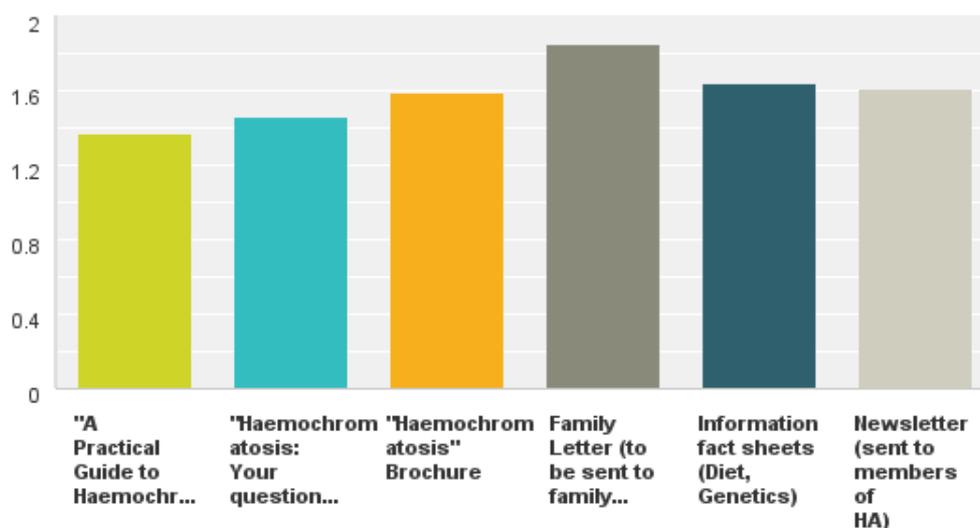


Table 4: Summary of Ratings for HA Print Resources
(311 respondents)

	Very helpful	Somewhat helpful	Undecided	Not very helpful	Very unhelpful	N/A	Total	Weighted Average
"A Practical Guide to Haemochromatosis (large detailed white booklet)	43.62% 130	15.10% 45	3.02% 9	0.67% 2	0.00% 0	37.58% 112	298	1.37
"Haemochromatosis: Your questions answered" (small red booklet)	36.59% 105	17.77% 51	3.48% 10	0.35% 1	0.35% 1	41.46% 119	287	1.46
"Haemochromatosis" Brochure	32.42% 95	21.50% 63	5.12% 15	0.34% 1	0.68% 2	39.93% 117	293	1.59
Family Letter (to be sent to family members advising them to be tested for HH)	19.22% 54	14.59% 41	6.76% 19	2.49% 7	0.36% 1	56.58% 159	281	1.85
Information fact sheets (Diet, Genetics)	27.40% 77	20.28% 57	4.63% 13	0.71% 2	0.71% 2	46.26% 130	281	1.64
Newsletter (sent to members of HA)	33.11% 98	20.27% 60	6.08% 18	1.01% 3	0.34% 1	39.19% 116	296	1.61

The resource with the lowest overall rating was the family letter. This was also the least accessed resource with only 122 participants providing a rating.

The most accessed resource was “A Practical Guide to Haemochromatosis” rated by 186 participants and received the highest average rating.

It should also be noted the high percentage of people who provided a rating of “N/A” for each resource or who chose not to answer the question at all. This may indicate a lack of awareness or availability of resources.

Participants were asked to comment on how these resources could be improved. 73 people provided feedback, which is summarised below.

Common Themes

- 27 participants indicated they were unaware of the existence of any of these resources.
 - “I have never been given any information”
 - “Didn’t even know they had resources. Perhaps GPs should be more aware it’s available so they can let people know”
 - “I’ve never seen these but would like to”
- 3 participants indicated they were unaware of the diet fact sheet.
- 3 participants suggested that more information about diet needs to be included in resources.
- 13 participants commented on poor availability of these resources or the need for them to be more visible in health service settings.
- 2 participants had noticed an improvement in the availability of resources over the years.
- 7 participants provided positive feedback and praise for print resources.
 - “I think these are a great resource as is.”
 - “They don't need improving - they're fantastic!”
 - “HA is to be congratulated for doing a brilliant job, which must in the long run tend to save many lives.”

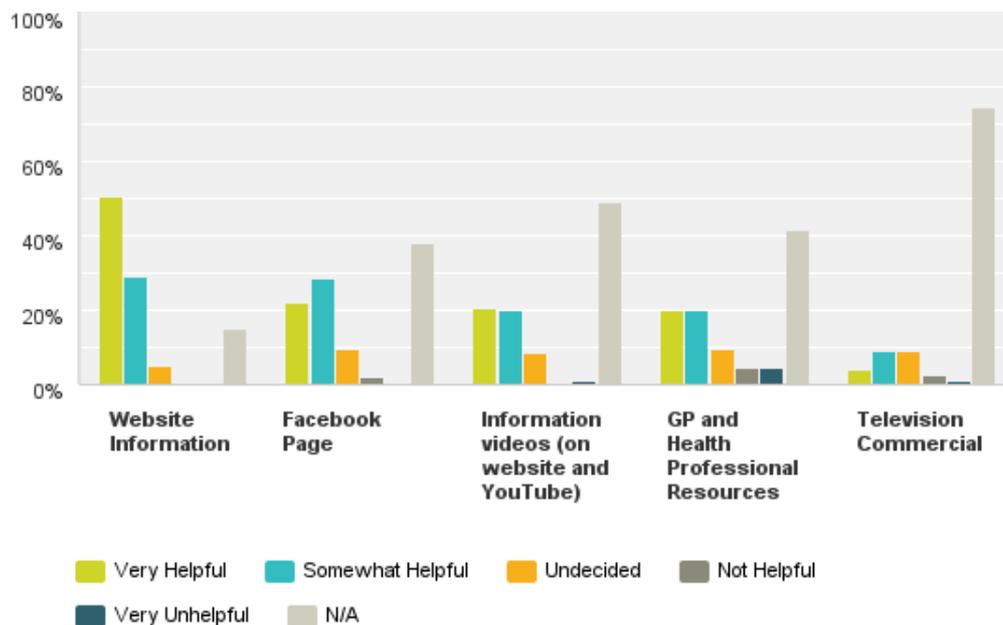
Further comments/suggestions

- Information is hard to follow and understand. It “blurs some topics and in others reads like gibberish.”
- “Unimaginative and old fashioned. Whole system needs an update, with increasing interest in ancestry you could easily update the program with “What else did your ancestors give you!” ”
- Reported difficulty understanding and then explaining genetics and implications to family members e.g. why one sibling has Haemochromatosis and not another.

- A need for more information on what to expect as people age and the long term implications of Haemochromatosis.
- A desire for more information on the impact of certain foods, medications and naturopathy/homeopathy can have on serum ferritin levels.
- Need to raise awareness of importance of passing information on to relatives.
- Suggestion that the history of where Haemochromatosis comes from needs updating (has origins in a larger region of Europe than specified).
- A desire for more frequent newsletters.
- “HYQA – needs mention of the first blood test being iron Studies”
- Practical Guide – needs to be kept up to date. Eg “hepcidin factor, current research, photos & diagrams”. Recommendation of www.haemochromatose.fr in Nimes as good example. Suggestion of inclusion of information re Osteo Necrosis or Avascular neurosis.
- Resources should be available online and be searchable.

Question 7 asked people to rate how helpful they found the current range of online resources provided by Haemochromatosis Australia. 310 participants responded to this question.

Graph 6: Average rating of HA Online Resources
(1=very helpful, 5=very unhelpful)



**Table 5: Summary of Ratings of HA Online Resources
(310 responses)**

	Very Helpful	Somewhat Helpful	Undecided	Not Helpful	Very Unhelpful	N/A	Total
Website Information	50.33% 152	29.14% 88	4.97% 15	0.33% 1	0.33% 1	14.90% 45	302
Facebook Page	22.22% 62	28.67% 80	9.32% 26	1.79% 5	0.00% 0	37.99% 106	279
Information videos (on website and YouTube)	20.51% 56	20.15% 55	8.42% 23	0.73% 2	1.10% 3	49.08% 134	273
GP and Health Professional Resources	20.14% 57	19.79% 56	9.54% 27	4.59% 13	4.59% 13	41.34% 117	283
Television Commercial	4.07% 11	8.89% 24	8.89% 24	2.59% 7	1.11% 3	74.44% 201	270

Overall ratings for HA’s online resources were fairly positive. HA’s Website was the most accessed resource overall with 257 participants providing a rating.

The television commercial was only rated by 69 people, with many indicating they had not seen it. This resource also received the lowest ratings.

The category “GP and Health Professional Resources” was meant to refer to the online resource category offered through HA’s website. The ambiguous nature of this title, means it is likely that people rating this item, understood it as information they had personally received through health practitioners. Therefore, data in this category is likely to be compromised.

Participants were asked to comment on how these resources could be improved. 57 people provided feedback, which is summarised below.

Common Themes

- 7 participants reported that they were unaware of some of these resources.
- 4 participants indicated they thought GPs need to provide more information/resources to patients.
- 2 participants indicated they felt HA needed to keep updating information available.
- Another participant felt information needed to be updated and “Bring it into the 21st Century”

Further comments and suggestions

- In relation to the website, “Plain English, keep it short, keep it simple. Make the landing pages suitable for those new to the condition. Let those pages link to deeper data.”
- Need to include a “full and up to date list of where venesections can be carried out as not everyone is suitable to be venesected at the blood bank”
- In relation to the Facebook page, “questions are not answered. Contributions there get buried very quickly.”
- Short, sharp animation or video is needed.
- “Explain to the public what this condition can do to other organs in the body so they all get tested.”
- A number of comments to this question focused on awareness and distribution of information which are issues discussed in later questions.

Question 8 asked people to rate how helpful they found the current range of online resources provided by Haemochromatosis Australia. 292 participants responded to this question.

Graph 7: Average rating of “Other” HA Resources
(1=very helpful, 5=very unhelpful)

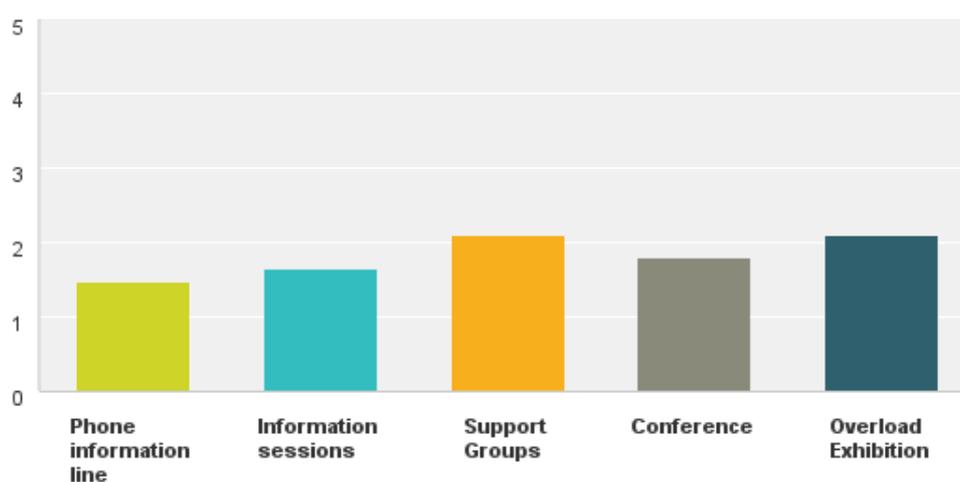


Table 6: Summary of Ratings of “Other” HA Resources

	Very helpful	Somewhat helpful	Undecided	Very unhelpful	Very unhelpful	N/A	Total	Weighted Average
Phone information line	13.17% 37	5.69% 16	1.42% 4	0.00% 0	0.36% 1	79.36% 223	281	1.48
Information sessions	8.49% 23	5.17% 14	1.85% 5	0.00% 0	0.37% 1	84.13% 228	271	1.65
Support Groups	6.57% 18	5.84% 16	1.82% 5	0.36% 1	1.82% 5	83.58% 229	274	2.09
Conference	6.88% 19	2.54% 7	2.54% 7	0.36% 1	0.36% 1	87.32% 241	276	1.80
Overload Exhibition	2.20% 6	3.66% 10	1.83% 5	0.00% 0	0.37% 1	91.94% 251	273	2.09

A very low percentage of respondents had accessed these resources. The phone information line received the highest average rating and had the most access.

Participants were asked to comment on how these resources could be improved. 43 people provided feedback, which is summarised below.

- 5 participants indicated they were unaware of these resources.
- 7 people reported these resources were unavailable in their area.
- Several people indicated an interest in attending information sessions if available in their area.
- 1 participant suggested more promotion of groups/information sessions is needed.
- 2 people indicated sharing stories/experiences with others was valuable.
 - “Good to connect with people in the same situation”
 - “Good to hear what worked for others”.
- In relation to information sessions; “Above my level of understanding when the experts gave their presentation.”
- Several comments to this question focused on information and awareness which are issues discussed in later questions.

Cross Promotion of Resources

Consideration of greater cross promotion of different HA resources may be useful. The survey identified people who had accessed some HA online information but were unaware of print material and vice versa. Another person had seen the website but was unaware of the Facebook page. While brochures do provide a web link and the website provides printable resources etc, perhaps providing more obvious links and cross promotion of resources may be beneficial in maximising people’s access to relevant information and support.

There are also cases where there does not appear to be any obvious cross promotion. For example, the “Overload” exhibition has a Facebook page for promotion of the event, but I was unable to locate a link to it from the HA Website or HA Facebook page. This may be a missed opportunity for raising the profile of the event.

Other Support and Information

Question 9 asked participants what other support and information has been helpful to them. 106 people responded to this question. Common themes are summarised below.

Specific Resources Identified

- Iron Disorders Institute (USA) – 8 comments
 - Guide to Haemochromatosis
 - Hemochromatosis Clinical Management Form
 - Hemochromatosis Diagnosis Algorithm
- Iron Tracker App from the Canadian Hemochromatosis Society
- Arthritis Australia website (which refers to haemochromatosis)
- Living Well with Haemochromatosis by Ralph Catalese
- The Haemochromatosis Cookbook by Cheryl Garrison – 2 comments
- The Rusty Kettle (Facebook group)
- Research by Professor Powell – 3 comments
- The Bronze Killer by Marie Warder
- Subscription to medical journal, “Medifocus” for up to date research on Haemochromatosis.

Information on diet and food was identified as being important to some people, with 5 people identifying the following supports as being beneficial;

- Diet information
- Dietician support
- Reading food labels – understanding many commercial foods are fortified.

Online resources were frequently mentioned in general terms as important sources of support and information.

- Online support groups – 2 comments
- Websites and online forums – 18 comments
- FB Groups – 12 comments
- A well informed moderator on online groups was identified as important with the quality of support and information dependent on this – 2 comments.
- You tube clips helpful for explaining the condition to family and friends.
- Twitter.
- Email communication.
- Canadian and Irish websites – 2 comments

Support from appropriate health professionals was identified as important.

- GP and specialists – 9 comments
- Bloodbank – 2 comments
- Venesection nurse
- Specialist – 3 comments
- Naturopath
-

Other support/information identified as being important are listed below.

- Sharing stories with other people with Haemochromatosis– 5 comments
- Being an advocate and helping raise awareness – 2 comments
- Support group – 2 comments
- Books – 2 comments
- Medical journals – 3 comments
- Natural remedies in medical journals
- Research articles
- Knowing that Haemochromatosis was causing my bipolar
- Information on fibromyalgia

In answer to this question, several participants also identified things they would like more information about or how support could be improved.

- Simple information would be useful “everything I have read is very textbook or medically written. A little more laidman would be helpful”
- Improved GP knowledge and awareness – 3 comments.
- More information on different types of Haemochromatosis and more research articles.
- Information on the impact of Haemochromatosis hormonally, and the impact of pyroluria on iron and ferritin.
- Raising awareness through blood bank.
- Need for greater awareness
- Some online groups too ‘sensational.’ Need for factual, relevant information.
- Online support forum was not moderated by a knowledgeable person. Jokes and social chatter more prevalent than information.

Question 10 asked people with a diagnosis of Haemochromatosis what they wish they’d known earlier. 121 participants provided comments.

- That the GP/HP had provided more information – 13 comments.
- That the GP or health practitioner was better informed/knew more about Haemochromatosis – 27 comments
- An earlier diagnosis – 23
- Wish that they hadn’t been taking a multivitamin.
- Known that breakfast cereals were often fortified with iron.
- More about diet and whether it makes a difference – 4 comments.
- Information re calcium restricting iron to liver and vitamin C enhancing iron to liver.
- Better understanding of the consequences of not being tested or following up on treatment – 4 comments
- Awareness of support and information available – 3 comments

- More about genetic testing (eg that basic blood test for iron is not definitive) – 4 comments.
- More awareness of hereditary nature and the need to encourage family members to be tested – 13 comments.
- That carriers of the gene might not have symptoms.
- More information about heterozygotes (and those with mild overloads) rather than a focus on C282Y homozygotes – 2 comments.
- More awareness of ‘rare forms’ of Haemochromatosis – 2 comments.
- Up to date information showing latest findings.
- Better dietary advice rather than conflicting information.
- Psychological impact of Haemochromatosis.
- Need more mention of psychological effects and depression that can accompany the physical disease.
- “Why my hands are red.”
- What to be aware of when pregnant.
- That its possible to have Haemochromatosis and become anaemic.
- “Option of getting a fistula inserted to make venesections quicker and less painful. Also cannulas instead of 18g needles.”
- “the adverse effect of venesections can be lessened by hydrating the body with saline at the same time”
- Long term effects of taking blood leading to high levels of bonded iron.
- Information on impact of drugs such as nexium on iron uptake – 2 comments.
- Listening to people’s stories.
- Information re where people can have venesections (and if they charge or bulkbill) – 2 comments.
- Better communication between GP and blood bank.

Suggestions for improving experiences

- Need early screening and checking of iron levels as routine – 4 comments
- Newborn screening
- Need for a national register of our genetic mutations that is accessible to the public.
- Better promotion of iron overload – dominant discourse is that we need MORE iron – 3 comments.
- Brochures on display.

Question 12 asked participants what would have helped earlier diagnosis. 188 people responded to this question. Responses are summarised below.

- Routine blood screening for iron/ferritin – 34 comments
- Health professionals having increased knowledge/awareness – 69 comments

- Listening to my GP and taking it seriously – 2 comments
- Family sharing knowledge – 15 comments
- More public awareness – 37 comments
- Better screening as routine/having a standard genetic test done at particular age (30s, 50's, baby all mentioned) – 17 comments
- Medical doctors available online Australia wide for people who move frequently
- “More understanding of rare genetic forms and treatment”

Raising Awareness

Question 13 asked participants how we can increase awareness of haemochromatosis. 154 people responded to this question and responses are summarised below.

General suggestions

- More advertising and public awareness campaigns – 42 comments.
- Television Commercials – 27 comments.
- Radio – 4 comments.
- Social Media – 13 comments.
- Newspaper and magazine articles/advertising – 9 comments.
- Posters.
- Red Cross blood bank advertising.
- Internet blogs.

Health professional settings

- Increased education and awareness of GPs and health professionals – 33 comments.
- More brochures/posters/advertising in GP clinics and Health clinics/hospitals – 16 comments.
- Standard genetic testing – 3 comments
- Serum ferritin as routine test, same as serum cholesterol in 50's.
- Iron studies included in all routine blood testing – 11

Other Methods

- A “Travelling roadshow” to get information out to the public.
- A public appeal.
- Raffles and pie drives/fundraisers/charity events with proceeds to research – 3 comments
- Raise awareness through speaking at local organisations and businesses – 3 comments.
- Storylines in popular TV shows and current affairs programs – 3 comments.

- Word of Mouth – 7 comments.
- Lobby health minister/governments, and reinforce saving money through routine testing and early diagnosis – 3 comments.
- Education in schools.
- Forming partnerships with other related health organisations.

Type of Information

Several participants identified specific types of information they feel needs to be conveyed to better raise awareness.

- Reinforce how common Haemochromatosis is – 3 comments.
- Encourage people with Haemochromatosis to tell family members – 3 comments.
- Explaining the origin of Haemochromatosis.
- Having less technical ads/pamphlets (keep it to the point and more scary; keep it short and simple) – 2 comments.
- Case studies –sharing of people’s stories
- Finding a respected/famous figurehead to promote the cause

Summary of Data from Participants without Haemochromatosis Diagnosis

52 people completed the survey, who identified that they do not have Haemochromatosis. Participants were asked how they first heard about Haemochromatosis. 26 people responded to this question.

- 81.48% identified they have a friend or family member with haemochromatosis.
- 37.04% reported having a known family history of Haemochromatosis.
- 3 respondents indicated they knew someone with Haemochromatosis, 1 identified as a health practitioner and 4 indicated they had heard about the condition through “other” means.
- 5 respondents commented that they were carriers of the condition.

Participants were asked to rate how useful they had found any HA print material they may have accessed. 26 people answered this question. As with the previous group (with known diagnosis of Haemochromatosis), the ratings for each item were generally very positive.

- The family letter and newsletter were the only items to receive ‘unhelpful’ or ‘very unhelpful’ ratings.
- Large percentage did not rate these items or indicated a response of N/A suggesting they had not accessed them.

4 participants provided comments for this question.

- 2 comments indicating they were unaware of resources

- Letter identified as useful for explaining need for a blood test to doctor.
- Would like to access hard copy of resources.

Participants were asked to rate how useful they had found HA's online resources. 25 people responded to this question.

- Facebook page and TVC were the only two items to receive negative ratings.
- The website was the most frequently accessed resource.
- As with the previous group, the ambiguous nature of the title "GP and Health Professional Resources" means this category is likely to be compromised.
- Large percentage did not rate these items or indicated a response of N/A suggesting they had not accessed them.

4 participants provided comments for this question which are summarised below.

- 2 comments suggested more TV advertisements/coverage would be beneficial
- Identified need for more GP awareness and better promotion of resources in health care settings.

Participants were asked to rate "Other" resources offered by HA. 23 people responded to this question.

- Very few people indicated they had accessed any of these resources.
- All ratings were positive or undecided.

2 people provided comments which are summarised below.

- Suggestion for Overload exhibitions Australia wide or other arts areas providing information nights.
- Suggestion for a concert for Haemochromatosis.
- Reported challenging relationships with doctors.

Participants were asked what other support or information they had found useful. 7 people provided comments, which are summarised below.

- 2 people indicated doctor information was important.
- Word of mouth
- UK based websites and genetics pages.
- Extensive web searching.
- Cookbooks
- Intention to read "The Iron Elephant."

Participants were asked how we can increase community awareness of Haemochromatosis. Ten people responded to this question, which are summarised below.

- Blood test and follow up with carriers and those who have it.
- Promote symptoms on TV and the press.
- TV advertising – 2 comments.
- Advertise broadly.
- “Keep talking and keep it simple”
- “Information and activities designed for science classrooms” (in schools)
- Sharing stories on TV programmes.
- Promotion through pharmacies and allied health professionals.
- Guest speakers at Men’s Sheds.

Survey Limitations

It should be acknowledged that there were some limitation in the scope of the population surveyed in this project. Being an online survey, input from those with limited internet use or access has been limited.

In addition, all participants had a basic level of literacy to be able to read, understand and respond to survey questions. The survey likely does not capture experiences of people with lower literacy levels. The survey also relies on contributions of people alert to and relatively engaged with the condition enough to volunteer to respond.

The demographic participating in this project were largely people engaged with HA in some way (as member or accessing Facebook/website). While this is useful for gaining feedback on HA resources, it misses information about what other resources these people may have accessed and their alternative experiences of support and diagnosis.

It should also be noted that while there is allowance for feedback from health professionals within the survey structure, the main feedback sought was from people with a diagnosis of Haemochromatosis. Survey promotional material did not target health professionals specifically and this may be an area for future investigation.

Recommendations and Discussion

1. **GP and Health Professionals** play a pivotal role in diagnosis and treatment of Haemochromatosis. Information provided by health professionals is identified as the most important source of support for participants in this survey.

However, a high percentage of participants report ongoing challenges in their experiences of diagnosis and treatment of their condition. Throughout the survey, there were comments of doctors' lack of awareness of the condition, confusion over testing and misinformation. Some people felt their GP's just did not take the condition seriously.

Given the pivotal role health professionals hold, ongoing education and building of awareness in this sector will be crucial in minimising harm from Haemochromatosis in the future. It may be useful to conduct a survey or specific review of GP and Health Professional resources currently provided by HA.

2. **Promotion of Available Resources.** Participants repeatedly commented that they were unaware of many of the resources offered by HA and indicated a desire to access them. Consideration of how to further promote availability of information and support may be useful.
3. **Genetics and Family History.** Given the hereditary nature of Haemochromatosis, only a small proportion of respondents indicated that a known family history contributed to their diagnosis. In addition, there were numerous comments throughout the survey suggesting confusion over explanations of genetics, a lack of sharing of information about diagnosis with other family members, or a reluctance of family members to be tested, despite known family history. This could be an important area to focus on in promotion of awareness.
4. **Potential Serious Health Implications.** A number of participants indicated they had not known how serious the health implications of the condition could be. This resulted in reluctance to be tested, poor engagement with treatment and low motivation to pass on information to family members. A number of participants also felt health practitioners had not taken the condition seriously.
5. **More information.** There were a number of comments throughout the survey that indicate participants would like more access to certain types

of information which are identified in the results. However, common themes included the following;

- Diet
- Information on how different drugs interact with Haemochromatosis.
- Rarer or less common forms of Haemochromatosis. Participants felt information on less well known types of Haemochromatosis was limited and hard to find.
- Psychological effects
- Keeping information up to date

6. **Sharing Stories and Experiences** was identified as a positive experience for many participants. For some people it was reading stories in the newsletter, others engaging in online forums or social media networks, or participation in face to face support groups or information sessions. Validation of lived experiences through sharing of stories and the passing on of knowledge around resources and support available were notably valuable sources of support.
7. **Keep it Simple.** A number of participants indicated they had trouble understanding certain information provided to them. For some it was not understanding information from health professionals, others had difficulty understanding HA written information or trouble engaging with the academic nature of an information session they'd attended. These comments indicate a need to ensure availability of simple, easy to understand information.
8. **Research.** Another portion of respondents indicated an interest in accessing up to date research and academic articles about Haemochromatosis, identifying this as an important source of ongoing information and support.
9. **Online vs Print.** Online resources were identified as the most popular source of information. However, given it was an online survey, this indication is perhaps an unsurprising result from the responding demographic. Even among this group, print information was still identified as an important source of information. Perhaps some stronger cross promotion of print and online resources would help with raising awareness of the diversity of available information.
10. **Public Awareness.** Survey participants confirmed a need for increased awareness of Haemochromatosis. Several commented on never having heard of haemochromatosis prior to diagnosis, not understanding the

seriousness or lack of awareness among health professionals. Ideas and suggestions from participants are listed in the results.

- 11. Routine Testing.** Many participants commented on supporting introducing some form of routine testing or screening for Haemochromatosis to limit harm.
- 12. Other Resources.** Participants suggested a number of resources that have been helpful to them over time. The ability to share stories and resources as previously discussed has been an important source of support for many people. Perhaps consideration could be given to keeping an evolving list of useful resources suggested and reviewed by people using the website.

Health Literacy Review

The World Health Organisation defines health literacy as ‘the cognitive and social skills which determine the motivation and ability of individuals to gain access to, understand and use information in ways which promote and maintain good health’ (WHO, 1998).

A study by the ABS (2006) found that only 41% of Australians aged between 15-74 years were assessed as having adequate health literacy skills. It is widely understood that low health literacy rates means lower rates of health service use and worse health outcomes (Batterham et al, 2016).

The term health literacy began as an idea focused on people’s ability to read and understand written information (Batterham et al, 2016). In consideration of the participant group completing the online survey, it is likely that most had a reasonable literacy level to be able to read, understand and provide answers to the questions presented. However, even within this group, there were comments that suggested some people had difficulty understanding some information provided by HA resources.

“Everything I have read is very textbook or medically written. A little more layman would be helpful”

Some made suggestions that resources could be improved by simplifying the language and information.

“Plain English, keep it short, keep it simple.”

The concept of “health literacy” not only covers people’s ability to read and understand information, but also their ability to seek out and access information and support from different sources (Batterham et al., 2016). Support networks and social skills impact of people’s ability and confidence to ask appropriate questions and engage in health discussions. Following from this, the term also considers people’s ability to critically analyse the information they access to make informed decisions about health (Nutbeam, 2000; Peerson & Saunders, 2009).

There were a number of examples within the survey of people demonstrating an ability to conduct their own research, question advice and share information with health practitioners to gain appropriate diagnosis and treatment.

“GP was not able to interpret gene test results correctly. She thought I was a heterozygote rather than compound heterozygote. It was only when I asked for a copy of the results that I discovered I was C282Y/H63D. Due to my own research I was able to inform the specialist of this”

“If I had believed my first diagnosis, I could have gone on for many more years undiagnosed, and done much more damage to my organs. My own Internet research in 2010 led me to think I may have it, so I asked my GP to be tested.”

“...I knew from my own research this not to be true, I asked for another iron studies test... which revealed incredibly high SF levels in so far Dr rang me in a panic!”

However, there were also a high percentage of people who indicated having had complex pathways to diagnosis and not having been able to access appropriate information and support. Various studies in recent years have confirmed that a high percentage of Australians do not necessarily have adequate skills to access appropriate health information and support (ABS, 2006, Barber et al, 2009).

To achieve HA’s goal of no Australian suffering harm from Haemochromatosis, it is important to consider the impacts of low health literacy in Australia and how this may effect people’s ability to access appropriate information and health care.

Perhaps the obvious focus is the need for continued education of GP’s and health practitioners to raise awareness of the condition. However, the other important factor is being able to provide alternative sources of information, to increase people’s confidence to ask questions about Haemochromatosis diagnosis and enable them to make informed decisions about their health care.

Communication failures are one of the most commonly cited underlying cause for complaints about the health system (ACSQHC, 2013). Provision of simple, easy to understand information is critical for improving health literacy. The scope of this report gave consideration to ways of improving the accessibility of current HA resources.

Target Audience

Through consideration of current HA resources, information appeared to fall into four main categories aimed at different target audiences.

1. **Building awareness** – Information in this category targets people who are largely unaware of Haemochromatosis or know very little about it.

The aim is to provide basic facts, and build community awareness. It may serve a secondary function of being a reminder to people with a known family history of HAEMOCHROMATOSIS. Examples of this type of resource include the small DL Brochure and the television commercials.

2. **Increasing knowledge** – This information aims to broaden the knowledge and understanding of people who already have some basic familiarity with Haemochromatosis. This may include people who've heard about it and want to know more, those with a known family history, people with a recent diagnosis, or support people. It's about tapping in to curiosity and interest and gently expanding knowledge. Examples of HA resources include the You Tube animation or the "Haemochromatosis, Your Questions Answered" booklet.
3. **Ongoing support for those with a diagnosis** – Once people have a known diagnosis of HAEMOCHROMATOSIS, availability of information and support becomes increasingly relevant. This information might include more detailed information on living with Haemochromatosis and ongoing management of the condition. Different people will be interested in different types of support and information. Examples fitting this category include the HA newsletter or "A Practical Guide to Haemochromatosis" booklet.
4. **Resources for GPs and Health professionals** – GP's and health professionals provide a pivotal role in supporting early diagnosis and raising awareness of Haemochromatosis in the community. Ensuring health professionals are aware of Haemochromatosis and have access to relevant information plays an important role in early diagnosis and sharing of resources and information.

Language and Communication

There is consistent evidence that the reading level of most health information (in print and online) is above the average adult's reading ability. (ACSQHC, 2013; WHO, 2013) The complexity of health literature becomes a significant barrier to people understanding, processing and acting on information about their health.

Health literacy advocates recommend keeping information simple and relevant. Simplifying language is not intended to insult a good reader or talk down to people. It should be conversational and if done well, good readers should be able to find out the information they want more quickly.

Below is a list of tips for increasing effectiveness of written and verbal communication. These dot points were compiled from a review of resources aimed at increasing accessibility of health information. A reference list is included below titled “Health Literacy Resources for Improving Written Communication.”

- Communicate the most important information first.
- Limit the overall number of messages.
- Keep lists or steps short (3-5 items only)
- Use short words and sentences
- Use common words, not jargon (including medical terms).
- Use the proper term before an acronym.
- Use practical information rather than philosophy.
- Tell the audience what action they need to take.
- Explain why this information is important to them, and what they will gain from taking action.
- Use a positive tone (rather than “do not fail to notify doctor if...” use “Notify your doctor when..”)
- Use an active voice (e.g. rather than “the medicine is to be taken before every meal” use “take medicine before every meal”)
- Write directly to your reader (use I, our, we, you)
- Use analogies familiar to people.

In considering current HA resources, there are some basic ways that information could be simplified to ensure greater accessibility. For example, when discussing common symptoms, instead of using “fatigue,” write “feeling tired all the time.”

Similarly, the phrase “Inherited Iron Overload Disorder” is often used as an alternative to the challenging name, “haemochromatosis.” This phrase is very descriptive if you stop to consider the meaning. However, for someone new to the condition, it could be perceived as another form of jargon and a bit of a mouthful to digest and understand. Simplifying it to “Iron Overload” may help with understanding. Once people’s attention has been captured, the hereditary nature can be discussed. Consistency of terminology is also obviously important.

These ideas around language and communication are relevant when considering all information provided, but maybe particularly relevant when considering the first group of resources, aimed at building awareness. With this in mind, some alternative wording for the DL brochure and family letter has been put together for consideration. Please see Appendix C.

Presentation of Text

The presentation of information is important in ensuring it is easy to read and highlights important points. The following dot points are compiled from the reference list below, titled, "Health Literacy Resources for Improving Written Communication."

- Use font size of at least 12points
- Serif fonts are easier to read.
- Use simple techniques such as bold to highlight important points.
- Limit use of italics, underlining or text in capitals as they are more difficult to read.
- Text boxes are effective for illustrating important points.
- Choose left justified margins - avoid centred text or fully justified margins in presentation of text. Gaps created can make text more difficult to read.
- Organise text so there is enough white space. Documents with too little white space can look crowded and discourage readers.

Visual Images

Using visuals in written communication help to tell a story and make information more appealing to read. However careful consideration should be given to how visual imagery is used. The following dot points are compiled from the reference list below, titled, "Health Literacy Resources for Improving Written Communication."

- Use simple visuals, avoid unnecessary details.
- 1 message per visual.
- Photos work best for showing real life events.
- Drawings can be good for showing medical procedures.
- Use visuals that help emphasise or explain text.
- Use simple captions that explain your image.
- Ensure images are not placed to interrupt the flow of text.
- Make the cover of documents attractive to your intended audience.
- Allow the cover to communicate the main message of what the document is about.

HA resources use visual images in a variety of ways, some of which are very successful in adhering to the suggestions compiled above. However, throughout the process of this review, I engaged in a number of conversations with people

about the current dominant image used by HA. The main image on most HA resources, portrays a very traditional and middle class, Caucasian family unit, including mum dad and two children. All family members are smiling, happy and perfectly groomed and presented.

Overall, it presents a very conservative image, not reflecting the diversity of our population, and resulting in the possibility that many people may find it difficult to connect with. Some survey respondents commented that HA resources appeared dated and in need of modernisation. In addition, the image itself does not tell the audience anything about Haemochromatosis. At a glance, it could equally be a brochure about family planning or any number of other health related topics.

It is assumed this image was chosen to represent the hereditary nature of Haemochromatosis and its European origins. However, without some background knowledge of Haemochromatosis, this is not obvious to the intended audience. Consideration of an alternative image that better illustrates an aspect of Haemochromatosis may be more useful in capturing attention and promoting awareness.

Health Literacy Resources for Improving Written Communication

Canadian Public Health Association (1998) "Easy Does It! Plain Language and Clear Verbal Communication Training Manual" National Literacy and Health Program, Canadian Public Health Association. Ottawa, Ontario. (ONLINE) Available at: http://www.cpha.ca/uploads/portals/h-l/easy_does_it_e.pdf [Accessed 3 October 2016]

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Online, Social Media and Other Communication

In general, the same health literacy considerations can be applied to online information. However, web users tend to scan content, picking out key words and phrases. Being succinct with information will help readers scan for relevant information. One suggestion is to limit the number of words to half what you would use for a print publication (TGDHAEMOCHROMATOSISS, 2014).

Simplifying language and navigation of HA's website, may promote greater accessibility and engagement. As one survey participant suggested,

“Plain English, keep it short, keep it simple. Make the landing pages suitable for those new to the condition. Let those pages link to deeper data.”

The advantage of websites is the ability for them to provide a range of information, links and suggestions. By keeping the presentation and language simple and accessible, people can navigate to locate topics of interest at a level that is suited to their needs. For some, this might be basic fact sheets, for others discussion forums or the latest academic research articles.

Keeping information up to date and relevant is important to maintain engagement with the target audiences and maximise support and information available. Survey participants identified a range of support and information outside HA resources that they have found useful over time. As suggested earlier in this report, one suggestion may be to provide a platform on the website for people to recommend specific resources and review them (a bit like Trip Advisor for people with Haemochromatosis!).

Boulos (cited in WHO, 2013, P63) points out the importance of social media in modern public health campaigns,

“Health organizations should go where people already are online (on social media), rather than just build their own isolated web islands of “read-only” information portals and expect people to come and visit.”

Social media platforms such as Facebook, Twitter, you tube have provided important opportunities for affordable public health communication that has the potential to improve people's capacity to obtain, process and understand health information (Boulos, 2012; WHO, 2013).

The survey identified that many participants value the opportunity to share stories, experiences and knowledge through platforms of peer to peer support

on various Facebook pages and online forums. This highlights the importance of HA's continued engagement with these communication platforms and seeking of opportunities to maximize these opportunities for engagement.

From observations of HA's current online resources, they appear to be largely used to share relevant information with people with a known diagnosis or active interest in Haemochromatosis. There is an additional opportunity to more actively utilise these forums for promoting broader awareness through advertisements, celebrity endorsements, compelling facts or information which people can be encouraged to share. Viral social marketing is identified as among the strongest aspects of social media, allowing organisations to reach out to many people, with minimal costs compared to other forms of advertising (WHO, 2013).

Building Awareness

In a world where we are never far from a smart phone, tablet, computer, or TV, we are constantly bombarded with information, advice and recommendations through advertisements on social media, websites and TV commercials. It is a reality that we all start to filter out information that does not have direct relevance to us or that does not immediately capture our attention. Everyone has certain ads or promotions that have stuck in their mind at certain times because they were particularly funny, annoying, caused fear or apprehension or provided stunning scenery or memorable imagery and catchy jingles that stuck with them.

Modern public health campaigns are competing with all this information to get a message to stick and broaden awareness. Despite this, education and health campaigns are an essential component of promoting health and preventing disease (Nutbeam, 2000). It is important that HA give consideration to finding ways to stand out and convey their message about iron overload through this jungle of information overload. Health communicators and educators can learn from the communication approaches successfully used by commercial advertisers and marketers (WHO, 2013).

There is some evidence that including health information within entertainment platforms can be a successful way of raising awareness of health issues (WHO, 2013). For example, seeking opportunities to be involved with television chat shows, have Haemochromatosis included in program story lines etc may be useful in raising awareness. These were also suggestions made by several people in the survey.

In all efforts to raise awareness of Haemochromatosis, the important point is to be clear about the key messages that need to be conveyed. Information needs to be simple and easy to understand to ensure maximum impact.

Television commercials (TVCs) were also frequently suggested in the survey as a way of raising awareness of Haemochromatosis. Short clips of information in a TVC are also useful for promotion on social media. If they are interesting enough, they are also the type of thing people are likely to share, further supporting promotion of the cause.

A TVC has very limited time to capture people's attention and deliver key information in a clear and concise way. It is important to remember the purpose is to raise awareness, and the main target audience is people who know very little to nothing about Haemochromatosis.

Taking into consideration the health literacy issues discussed in this report, HA's television commercial was reviewed. HA's current television commercial contains images of people who speak broadly about having symptoms, being a carrier and feeling better after diagnosis. Verbally, there is no information about what the symptoms are, how it is tested, how it is treated or how serious the condition could potentially be. Similarly, for someone who knows nothing about Haemochromatosis or genetics, what does being a carrier actually mean?

In scrolling text, the advertisement lists some symptoms, but relies on a literate audience and one who is engaged with the TVC to accurately pick up on this information. The audience needs to both read the information and listen to the audio to gain meaningful information.

If in the future, HA was in a position to develop a new television commercial, greater consideration of the target audience and key concepts to be conveyed, may support a stronger campaign. Taking on board health literacy tips discussed earlier in this report, keeping the language simple and accessible, and using imagery that supports the information provided, may help strengthen the message. Some creative ideas based on brainstorming with participants and stakeholders in this project are discussed in Appendix D.

Summary

The "Helping Haemochromatosis" project has provided a range of both quantitative and qualitative evidence for consideration in future activities of Haemochromatosis Australia. Recommendations for improving support and information have been discussed, and ideas put forward to help raise awareness in the broader community. It is hoped the information from this project can be useful for pursuing Haemochromatosis Australia's vision of no Australian suffering serious harm from haemochromatosis.

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Appendix A Focus Group and Interview Questions

PART 1

Exploring how people first learnt about HAEMOCHROMATOSIS and what led to diagnosis.

Question 1

How did you first learn about or hear about Haemochromatosis?

- GP/Family/Friends/Own research/general knowledge
- What led to formal diagnosis (including support received and/or challenges/barriers along the way)
 - early/late diagnosis
 - simple/complex pathways

PART 2

Support and Information received or that people have accessed.

Question 2

What information or support that you have received along the way has been particularly helpful?

- What stands out to you as something that was particularly helpful in being able to understand your diagnosis or feel supported?
- Eg. Verbal info from medical professionals, brochures, websites, conversations, etc.

Question 3

What information or support that you have received along the way has been notably unhelpful?

- Have you received any information or support that stands out as having been particularly unhelpful, confronting or challenging in your journey with HAEMOCHROMATOSIS?

PART 3

Evaluation of HA specific information and support.

Question 4

If you have accessed online HA support, what has been your experience of this resource?

Question 5

If you have accessed print information from HA, how have these resources been helpful/unhelpful?

Question 6

If you have accessed HA's phone service, what was your experience of this service?

PART 4

Reflecting on experiences of being diagnosed, accessing treatment and managing the condition.

Question 7

What do you wish you'd known earlier or what support would have been helpful on your journey?

- Any parts of the medical/treatment system or process that you think could be improved to better support people with HAEMOCHROMATOSIS?

Question 8

How do you feel about your current knowledge of HAEMOCHROMATOSIS and support available to you?

- What areas would you like more information/support around?

PART 5

Building awareness of HAEMOCHROMATOSIS.

Question 9

In your experience, how aware of HAEMOCHROMATOSIS have family/friends/community been?

- Have family members been open to being tested for HAEMOCHROMATOSIS as a result of your diagnosis? Or visa versa?

Question 10

What do you think would help to raise awareness of HAEMOCHROMATOSIS in the broader community?

- Who should we target?
- How do we go about raising awareness?
- Invite people to be part of organising an event to raise awareness of HAEMOCHROMATOSIS

Question 11

Any final comments/thoughts that people would like to add or that they think have been missed from the discussion so far?

Appendix B Please see attached PDF of Survey Questions from Survey Monkey.

This document largely considers information in the awareness raising category of information. In any rewording of these documents, as per health literacy tips, it is vital to consider what the 3-5 main points are that need to be conveyed to the intended audience. How can these points be worded as simply as possible with short succinct sentences? If people read the document and consider it important enough, they have the opportunity to follow up and find out more about the condition and read in more detail.

As someone new to haemochromatosis, I'm still learning about the condition and acknowledge that I may have misinterpreted some information in my suggested rewording. Those with more knowledge and expertise will be able to contribute to the ongoing review of these documents.

All suggestions made in this document are not intended as definitive versions of wording, but to promote consideration of stripping back information to only what is absolutely necessary and to consider ways of simplifying language to make it more accessible.

Haemochromatosis Australia DL Brochure

As discussed in the report, it is suggested the content of this document aims to introduce the topic of haemochromatosis to people who have never heard of the condition or know little about it.

The key points to convey might include:

- What is Haemochromatosis?
- What are the symptoms?
- How can people be tested?
- Why should people be tested?
- Where can people get more information?

In the example below, some language has been simplified and other sections removed. For example, the section on "Iron studies" may not be necessary for people learning about Haemochromatosis for the first time. It contains a lot of "medical jargon" that could be alienating to people and may be more relevant to

include in other resources. There is the potential to strip back information even more if deemed necessary.

Brochure Example

What is haemochromatosis?

Haemochromatosis is a condition that causes your body to absorb too much iron from the food you eat.

This iron is stored in your body and builds up over time.

It is sometimes called “Iron Overload Disorder” and can cause you serious illness if not treated early.

Haemochromatosis is a genetic condition, which is passed on through your family.

What are the signs and symptoms?

Everyone has different symptoms.

Some people don't have any symptoms at all.

The most common signs of iron overload are:

- Feeling tired all the time
- Pain in your joints.

What are more serious signs and symptoms?

- Unusual skin colour
- Arthritis
- Liver cancer
- Diabetes
- Heart problems
- Hormonal changes and losing interest in sex.

How can I be tested?

You can be tested for haemochromatosis through a simple blood test.

Even if you don't have symptoms, you might still carry the gene and pass it on to your children.

Talk to your GP about being tested.

How do you treat it?

Haemochromatosis is treated by giving blood. This removes excess iron from your body.

Your GP can help keep an eye on your iron levels and help you know how often you need to give blood.

If you are diagnosed early, you can lead a normal, healthy life.

Who is at risk?

Haemochromatosis is one of the most common genetic disorders.

If a close family member has haemochromatosis, you should be tested too.

Brothers, sisters, parents and children should all be tested.

People can develop symptoms at any age.

Men often develop symptoms between the ages of 40 and 60.

Women sometimes develop symptoms a bit later.

Where does it come from?

If your family originally comes from northern Europe, you might be at risk.

Haemochromatosis affects about 1 in 200 Australians with northern European ancestry.

How can I find out more?

Talk to your GP

Visit our website www.ha.org.au

Call our Info Line 1300 019 028

Haemochromatosis Australia Family Letter

In considering health literacy concerns and reviewing the family letter, it is clear that the letter contains a lot of information. The wording also introduces a lot of medical jargon that someone new to the condition, or someone with low health literacy, might find alienating.

The letter is also quite long, and does not allow much white space, which health literacy tips suggest will put readers off. By changing lists to dot points and scaling back information to convey only the key points, this may help make the information more accessible to people.

Key points to convey might include:

- Someone in your family has Haemochromatosis
- You might be at risk and should be tested too.
- Why should you be tested?
- How can you be tested?
- Where can you get more information?

Letter Example

Hello,

Someone in your family has been diagnosed with **haemochromatosis**. You probably should be tested too!

Haemochromatosis is a common genetic condition passed on from parent to child.

People with **haemochromatosis** absorb too much iron into their blood, which can cause serious health problems. If you are diagnosed early, you can lead a normal, healthy life.

People can experience symptoms at ANY age.

Early symptoms of Haemochromatosis might include;

- Feeling tired all the time
- Pain in your joints

In some cases, Haemochromatosis can lead to more serious health problems.

- Unusual skin colour
- Heart problems
- Diabetes
- Liver cancer
- Feeling out of sorts
- Arthritis
- Problems with your sex life or being uninterested in sex.

You can be tested for **haemochromatosis** through a simple blood test. Talk to your GP about being tested.

Even if you don't have any symptoms, you might still be a carrier and pass it on to your children without even knowing.

Treatment is very simple if you are diagnosed early!

If you would like more information,

Try our Website

www.ha.org.au

Or phone our Info line

1300 019 028

Appendix D Creative Brainstorming

The report reflects on the information overload we are bombarded with on a daily basis. It discusses the need to find creative ways of capturing people's attention to help raise awareness of haemochromatosis in the broader community. Throughout this project different creative ideas and strategies were discussed with participants and stakeholders that may be useful for consideration in future awareness raising activities.

Ideas aimed to come up with ways to capture attention through unique or captivating imagery that sticks in people's minds, by using humour, catchy jingles, quirky stories or anything to stand out in the jungle of information overload.

Overload Imagery

The Tasmanian Overload exhibitions have provided a huge range of visual representations of haemochromatosis. Some of these images may be able to be used in a creative way on HA's promotional material to capture people's attention and stand out from other, more traditional types of health promotional resources.

Awareness Event

Consideration could be given to staging a significant awareness raising stunt to gain media publicity. This might be something like an installation playing on the theme of "too much iron." Unusual events in public places are talking points and generate conversation.

- Collecting a huge pile of old irons and surrounding a single person with them as an illustrative installation in a public place.
- Having 100 people set up in a public place with irons and ironing boards as an installation showing "too much iron" (or in several locations around Australia for awareness week).
- Quality photographs of such an installation could be used on posters, social media and other HA resources to continue to raise awareness over time. If the event is interesting enough, people will take their own pictures to share on social media.

Use of puns and play on words

"Iron" and "Iron overload" provide a wealth of opportunities for using puns in creative ways to capture attention. While HA resources have a serious message

to convey, some use of humour and a playful twist may help to engage the audience and raise awareness.

Some of these phrases could have some great imagery attached and be used in posters, memes and social media campaigns or TVCs.

- “Iron Man” or “Iron Maiden”
- Feeling a little rusty?
- Ironing out the details
- Don’t get overwrought
- Treatment can help forge your own destiny
- Hammer your blood into shape
- Imagery using actual irons to convey key messages about symptoms or features of the disorder in a visual way.
 - A person sleeping with an iron on their head (fatigue)
 - An iron swinging on a cord and hitting someone in the knee (joint pain)
 - A parent handing a child an iron (hereditary nature of Haemochromatosis)
 - Someone unloading irons from pockets, around neck or carried (venesection).

Haemochromatosis is hard to say

While this is true, instead of it being a barrier, maybe this fact could also be used as part of a marketing strategy. Attention grabbing headlines on posters, memes, social media etc might include things like:

- “Haemochromatosis is hard to say!”
- “Haemo ...WHAT?”
- Six syllables makes for a long word, but consider its use if audio/visual are in the mix. Imagine a charismatic person with a maraca singing/sounding out the word in a playful way.
- Or if “haemochromatosis” is considered too big a barrier, perhaps consideration could be given to limiting its use and focusing solely on “Iron Overload” in HA resources.

Sharing Stories

The “Helping Haemochromatosis” project highlighted people’s appreciation for hearing real life stories and sharing experiences of their journey with haemochromatosis. This may also be a useful way of promoting awareness. An American photographer has become internationally recognised through his Facebook page “Humans of New York” that shares portraits of people and a snapshot of a conversation with them about an aspect of their life.

Perhaps this format could be used for promoting experiences of Haemochromatosis. The images and stories could be shared on social media or the website to illustrate who is affected, their experiences etc. It provides a human touch to facts and figures and different people will connect with different characters.

- Photograph of someone visiting a blood bank or having a venesection with a brief quote about their day and what they're doing.
- Photographs and stories of people of different ages/gender to illustrate how it can impact anyone.
- People sharing positive stories.
- People sharing challenges.
- People going about their daily business (showing Haemochromatosis does not have to be a major barrier to life).

Television Commercials

Television commercials (TVCs) provide limited time to capture attention and convey key points in a succinct way. However, if done well, they can also draw people in, and provide important information with minimal audience input. TVCs also have the advantage of being able to be shared on a variety of platforms (TV, Website, Social Media etc). While they can be expensive, its food for thought.

Using some of the ideas discussed above, this concept was discussed with project stakeholders as a different approach to awareness raising for TVC.

Narrator: **“Some people absorb have too much iron in their blood”**
Neutral background with figure standing in centre holding an iron.

Narrator: **“Do you feel tired all the time?”**
Shot of figure laying down, sleeping with an iron on their head.

Narrator: **“Do you have joint pain?”**
Iron swings by cord from right of screen, hitting figure in knee, causing them to react in pain.

Narrator: **“You might have Haemochromatosis”**
Figure: **“Haemo - what??”**
“Hae-mo-chro-ma-to-sis” sings/chants figure 2 dancing on screen with maracas. Leaves again.

Narrator: **“Haemochromatosis is a common genetic condition that is passed on through your family”**

Four figures of different ages standing in a line with an iron being passed from oldest to youngest.

Narrator: **“Its easily treated if diagnosed early.
If undiagnosed, it can lead to more serious health concerns.”**
(Potential to list other symptoms with visual representation)

Narrator: **“Symptoms are different for different people.”**
**“And some people might not have any symptoms but carry
the gene without even knowing.”**
Figure turns around to reveal an iron on their back.

Narrator: **“You can be tested for Haemochromatosis through a simple
blood test.
Treatment is simple and if diagnosed early, you can live a
normal healthy life.
So if you’re feeling a little rusty, talk to your GP about ironing
out the details.”**

Figure 2 **“Hae-mo-chro-ma-to-sis”** sings figure with maracas.