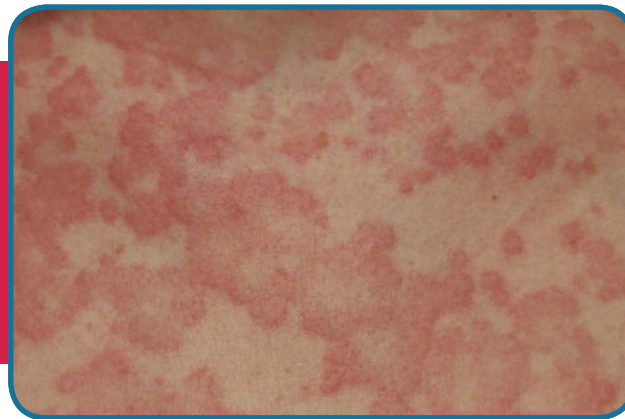


WHEELS OF DESPAIR

Chronic spontaneous urticaria:
breaking free from the cycle of despair





Foreword by Maureen Jenkins, Director of Clinical Services, Allergy UK

Chronic spontaneous urticaria (CSU) is a common and extremely distressing skin condition that causes red, swollen, itchy and sometimes painful hives or wheals on the skin. These wheals reoccur daily for at least six weeks and often for considerably longer, even for many years. We receive many calls to the Allergy UK helpline from patients with CSU who are at their wits' end as a result of their symptoms, which affect their sleep, work and self esteem.

The triggers for CSU are unknown and it could strike anyone from a child to a grandparent. The aim of this report is to establish the significant impact CSU has on the lives of patients and to outline what must be done to ensure they have access to the optimal care they deserve. Therefore it is vital that healthcare professionals and commissioners understand the role they can play in improving the quality of life of those with CSU and in ending the 'wheal' of despair in which patients are trapped.

Contents

Executive summary	3
Introduction	6
What is the burden of chronic spontaneous urticaria (CSU)?	7
Living with CSU	8
How is CSU currently diagnosed and treated?	11
A summary of the key challenges	16
A call to action	18
Conclusion	22
References	23

Executive summary

“ Having the condition does put a strain on my marriage, with my mood swings, sometimes when the condition is flaring up, you're scratching, you don't get much sleep so at times you're not the best person to live with... ”

Mark, 52, living in Sale, Cheshire

Chronic spontaneous urticaria (CSU) or chronic and severe 'hives' (to use the lay term) is an extremely distressing skin condition which has a significant impact on quality of life. CSU is characterised by red, swollen, itchy and painful wheals on the skin which may resemble nettle-rash. These wheals reoccur daily for at least six weeks and often for considerably longer. Each wheal generally resolves within 24 hours, but as one wheal resolves others develop so that some people can continuously suffer these symptoms for many years.

The effects of CSU on quality of life can be far-reaching; these include sleep deprivation, depression and social isolation. It has been reported that in comparison to some other dermatological and medical conditions, people with urticaria have a significantly worse quality of life.¹

This report reveals and outlines solutions to six key challenges faced by people living with CSU and clinicians alike:

- Lack of national guidance or prioritisation
- Lack of specialist knowledge of the condition in primary care
- Delay in referral and correct diagnosis
- Confusion between CSU and allergy
- Lack of psychological support for people living with CSU
- Lack of access to efficacious treatments and clarity regarding treatment options

In spite of the significant impact on a person's quality of life and ability to work, CSU, like many dermatological conditions is overlooked by the NHS. This intractable skin condition urgently needs prioritisation by healthcare professionals and commissioners to ensure people living with CSU receive the care they deserve to try and resolve symptoms, control the disease and vastly improve their quality of life.



CSU causes similar levels of emotional and psychological distress to that experienced by people with heart disease, (coronary artery disease) yet there remains a lack of dedicated services to tackle the needs of those living with CSU, or in fact any form of skin disease.^{7,8}



High personal and societal burden

Despite being relatively unknown, this debilitating skin condition is thought to affect between 318,000 and 630,000 people in the UK.^{2,3,4} To put this into context, this figure equates to the entire population of Manchester (which is 503,127).⁵ This condition has a huge impact on patients' quality of life.⁶

The latest findings from a new audit of those living with CSU reveal the great emotional, physical and psychological impact this condition can have:⁶

- **Nearly a quarter** miss work at least once a month due to their symptoms
- **Half (56%)** say that they do not have control over their symptoms
- **9 out of 10** state that their sleep is affected by CSU
- **Nearly half (46%)** feel like crying at least once a week due to their CSU symptoms
- **48%** are unable to take part in usual social activities, with **37%** reporting that their sex life is restricted
- **Nearly all (90%)** report that their CSU symptoms place limitations on their normal physical activity such as sports, hobbies, work and sex

Delays in diagnosis

Anyone can be struck by CSU, symptoms can appear with no warning and can persist for more than a year; urticaria (of which CSU is a specific type) is one of the most common reasons people seek medical advice.^{2,9} CSU can be difficult to diagnose and the referral pathway is not always clear to GPs. There is also considerable variation across the country, meaning it is not unusual for some patients to suffer for a decade with little or no symptom control.

GPs receive very little dermatology training (on average no more than six days) compared with other medical specialties.¹⁰ A survey conducted for this report found that many CSU patients have to wait as long as 18 months before they are referred to and diagnosed by a specialist.^{6,11}

Delays in diagnosis and insufficient access to treatment mean that people who live with CSU get trapped in a cycle – or *wheel* – of despair: waiting for symptoms to reoccur, waiting for a referral, waiting for diagnosis and waiting for effective treatment.

Lack of access to effective treatment

Once diagnosed, things may not improve. Until recently, antihistamines were the only licensed treatment for people living with CSU, however more than half of all people with CSU do not get any relief from their symptoms with licensed doses of antihistamine, which is the first-line therapy.³ Medical guidelines suggest that doctors increase the dosage up to four times the licensed dose; however 40% of people with CSU still do not experience relief from their symptoms from this increased dose.¹²

Second-line therapy suggested in guidelines involves treatment with unlicensed treatments such as montelukast and ciclosporin, which may be used to help control symptoms. Although not specifically designed or licensed to treat the condition, they may be successful for a percentage of patients. Recently, omalizumab, a drug that modifies the immune response, has been used with some success and has received a licence for the treatment of CSU. However, it will take time for the relevant specialised services commissioning groups to make this widely and directly available to the appropriate patients that need this treatment.¹³





Introduction

This report seeks to raise awareness of the real quality of life impact of CSU, in addition to highlighting the latest key issues associated with the diagnosis and management of the condition.

Often people living with CSU do not receive a diagnosis for 18 months or more from the point of first consultation. Once diagnosed, people with CSU are usually prescribed antihistamine treatments which are effective for some but leave up to half without symptom relief.³ Medical guidelines recommend that doctors increase antihistamines up to four times the licensed dose; however despite this, a proportion of patients will still experience the symptoms of CSU.¹²

Many patients do not experience appropriate escalation of treatment when they fail on first-line therapy. The result is that those living with the condition are trapped in a cycle – or *wheel* – of despair, characterised by the need for symptoms to be present at a medical consultation to trigger a referral, the possible temporary abatement of symptoms and the subsequent physical and psychological distress when they return. This is compounded by a lack of fast access to appropriate treatments once a diagnosis has been made.^{3,6,11}

The contributors of this report are issuing a call to action for more to be done to help resolve these issues and outline a set of recommendations on how the care of those living with CSU can be improved.

To support the development of this report, an audit of 103 people who have been diagnosed with CSU was undertaken to reveal the impact of CSU on the day-to-day lives of people living with the condition in the UK.⁶

This *Wheels of Despair* report has been developed from contributions of opinion made by a multidisciplinary taskforce including hospital specialist consultants, primary care professionals and Allergy UK, and is supported by Novartis Pharmaceuticals UK Limited.

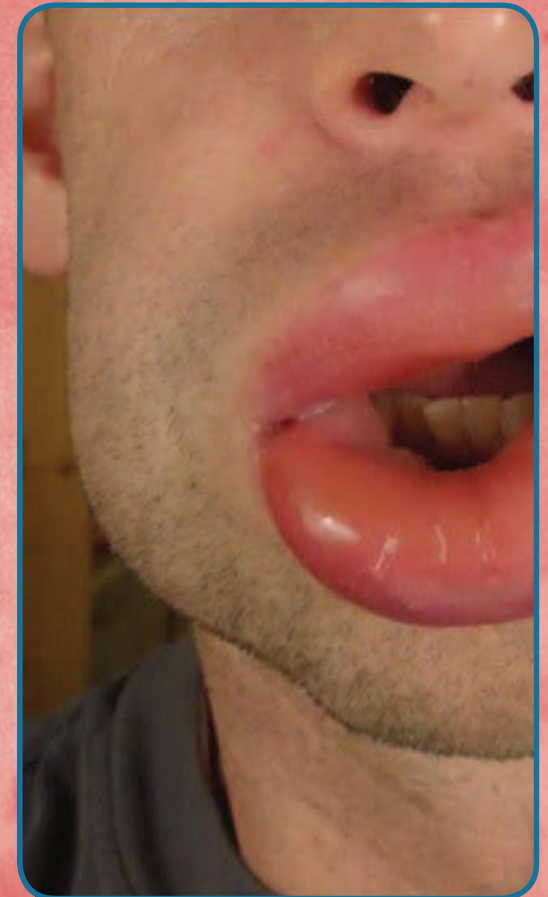


What is the burden of chronic spontaneous urticaria (CSU)?

Red, swollen, itchy and painful 'wheals' (hives) that recur daily, or almost daily for six weeks or more characterise CSU, a debilitating and distressing skin condition which is thought to affect as many as between 318,000 and 630,000 people in the UK.^{2,3,4,6,7} Urticaria (of which CSU is a specific type) is a very common reason why people seek the advice of GPs, paediatricians, dermatologists, allergists and even emergency medical care.^{3,9}

Urticaria is usually intensely itchy and can be extremely painful. Although each wheal may only last a few hours, new ones often appear at the same time as old ones are fading. The itch is often very persistent, even at night-time, and is sometimes accompanied by deep tissue swelling, particularly of the face, neck, hands and feet (this swelling is known as angioedema).¹⁴

Urticaria is described as 'chronic' when the symptoms present and recur daily or almost daily for more than six weeks.² It is described as 'spontaneous' when symptoms are not triggered by a known cause.





Women are twice as likely as men to be diagnosed with CSU and generally most people develop symptoms in their most productive years, between the ages of 20 and 40.³

CSU is thought to affect 0.5-1% of the population, a similar figure to those living with heart failure in the UK.^{3,7}

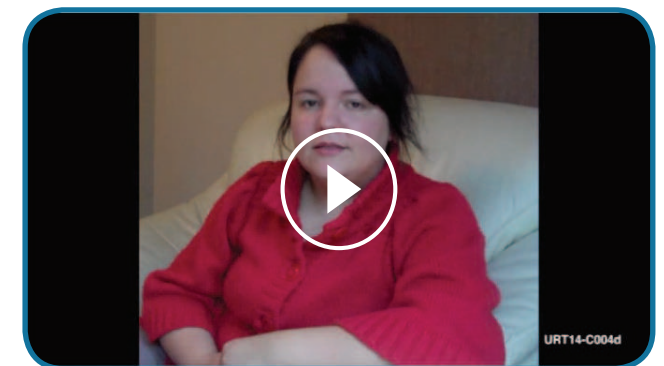
Symptoms appear spontaneously in CSU – there's no external trigger for the wheals and swelling that develops.^{3,9} Although GPs often carry out allergy testing to try and determine the cause or trigger of the symptoms, this is almost always futile as CSU is not caused by an allergen. With other types of urticaria the cause can usually be isolated, meaning the individual may feel more empowered to deal with the condition. The misery for CSU patients is that no cause can be isolated, which leads to more frustration. Research into the causes of CSU has suggested that the immune system may have a role to play in some with the condition, alongside other aggravating factors including stress and infection.^{3,15}

The severe and chronic physical impact of CSU leads to a significant detrimental effect on quality of life upon those living with the condition. A quality of life study has suggested that the negative impact of CSU is comparable to that seen in heart disease.⁷ A 'flare up' can often mean either missing work completely or decreased productivity when at work as well as avoidance of social activities.^{3,12} Other, negative physical and emotional effects of CSU on quality of life include sleep deprivation, depression and social isolation.^{3,7} Furthermore, nearly three quarters of people with CSU report that their condition interferes with their sexual relationships.⁷

Living with CSU

People living with CSU experience unpredictable outbreaks of itchy and painful wheals which can have a knock-on effect on their work, sleep, hobbies and social activities.³ Nearly three quarters of people living with CSU report having to miss out on social occasions because of their skin condition.⁷

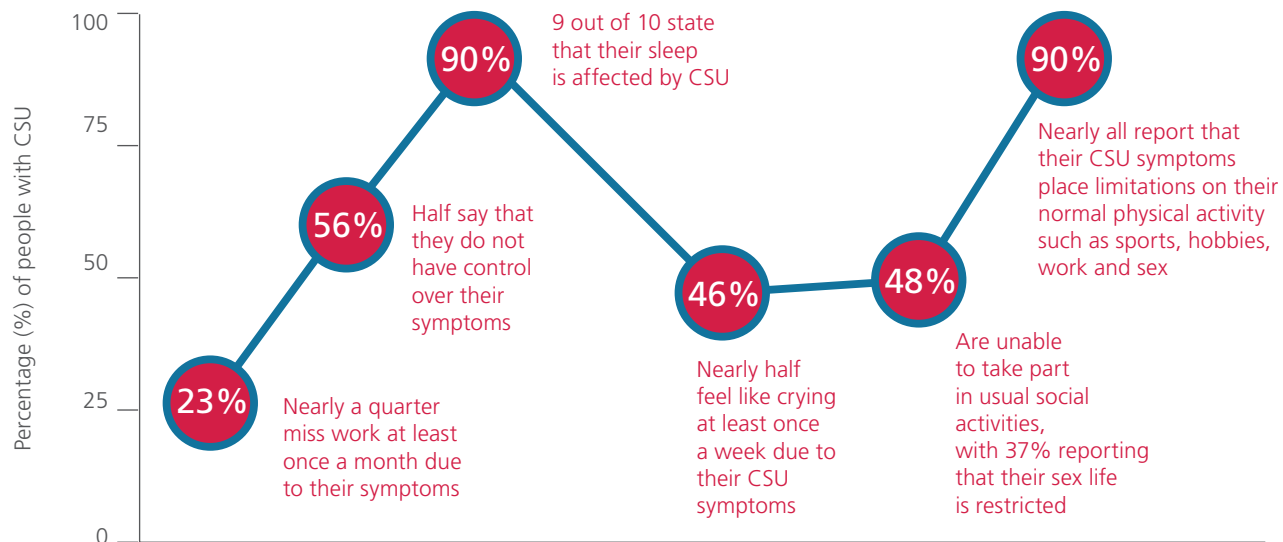
Most people living with the condition experience symptoms of CSU for at least a year, with a considerable proportion of people experiencing symptoms for much longer.³





“ The unpredictable nature of CSU has a strong emotional and psychological impact and is associated with a more substantial effect on quality of life than other skin conditions. Couple this with the cosmetic disfigurement and embarrassment sometimes caused by CSU and you can see why many patients suffer from anxiety and depression. We hear from sufferers who are in utter despair over their treatment and feel completely trapped by the condition. ”

Maureen Jenkins, Director of Clinical Service, Allergy UK





What does this tell us?

- CSU is a physically and emotionally debilitating condition
- A significant number of people fail to find any level of control over their symptoms, especially those that do not respond to first-line treatment, antihistamines
- Finding and gaining access to the right treatment can be difficult and may contribute to feelings of frustration, as people with CSU feel trapped in a cycle of despair
- Many think that their CSU symptoms exclude them from a normal lifestyle, which leads to psycho-social comorbidities like anxiety and depression



Having CSU can affect almost every aspect of a person's life, with clinical research demonstrating that living with the condition can increase an individual's risk of depression.³ Despite this, access to psychologists, psychiatrists and counsellors within dermatology services (psychodermatology) across the country is lacking. It is rare for people living with any form of skin condition, including CSU, to experience routine and easy access to psychological care. Again, there is a lack of consistency across the country with only three hospitals having a dedicated psychodermatology service, an offering that has deteriorated over the last ten years.⁸

How is CSU currently diagnosed and treated?

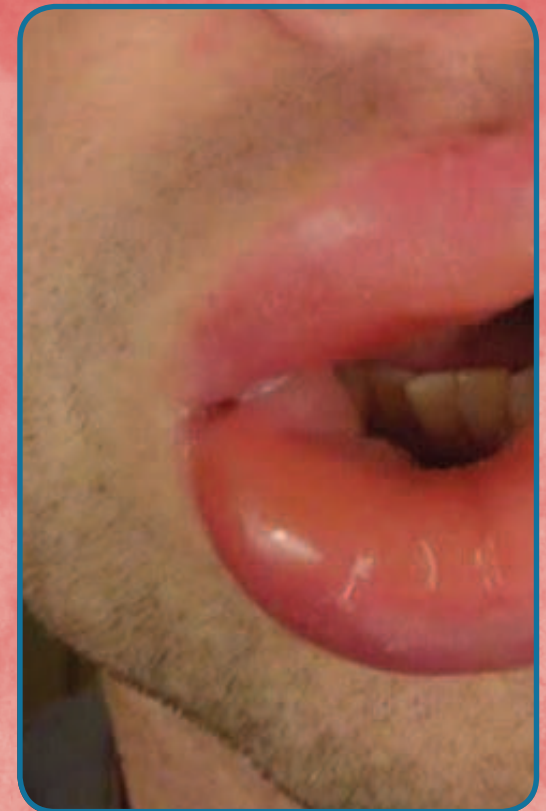
Diagnosis

- 1) CSU can be diagnosed with a detailed patient history. A GP will usually ask a patient to keep a symptom diary to record any potential triggers in order to exclude or confirm a diagnosis of CSU. It is important to record the onset, duration and course of CSU. The duration of the individual wheals and rash should also be recorded accurately. Any occurrence of angioedema should be noted.
- 2) Further tests may include evaluations of the skin, blood and urine.
- 3) If initial treatment is ineffective, GPs should refer patients to see a specialist dermatologist or immunologist for further treatment.

Treatment

Until recently, antihistamines were the only licensed therapy option for people living with CSU. Medical guidelines recommend doctors increase the dosage up to four times the licensed dose; however 40% of people with CSU still do not experience relief from symptoms from this increased dose.¹² Non sedating antihistamines are usually prescribed in the first instance, but sedating antihistamines may be prescribed, particularly at night to help with night time itch. However, patients may need to face the additional issues of dealing with fatigue and restriction on daily activities (such as driving), due to sedating treatment.

In the absence of alternative licensed treatments, guidelines suggest second-line therapy with drugs such as corticosteroids and montelukast. Third-line therapy includes treatments which act upon the immune system, such as ciclosporin, mycophenolate and methotrexate. Although not specifically licensed or designed to treat the condition, they may be successful in a percentage of patients. Recently, omalizumab, a drug that modifies the immune response, has received a licence for the treatment of CSU following publication of positive phase 3 trial data.⁹ The Specialised Dermatology Clinical Reference Group will make recommendations to NHS England on the inclusion of this treatment in a commissioning policy.



More than half of all people with CSU do not achieve symptom relief from licensed doses of antihistamines.³ There's a critical need for rapid access to the latest new treatment options as up to 40% of those with CSU fail even on increased antihistamine doses.¹²

Measuring the severity of CSU:

Once diagnosed, CSU disease severity should be measured using the Urticaria Activity Score (UAS). The UAS is based on the evaluation of numbers of wheals and the intensity of itching each using a 0-3 point scale. It is calculated as the daily sum of the wheal and itch score, with a maximum score of 6 points per day. Because of the fluctuating nature of urticaria, the UAS score should be recorded for 7 consecutive days, then added up to calculate the weekly Urticaria Activity Score (UAS7), which will give a score ranging from 0 to 42. A UAS7 score of 6 or less suggests that the CSU is well-controlled.¹⁶



Obstacles to treatment and diagnosis

Evidence suggests that dermatology services lack prioritisation within the NHS and that this can have an impact on patients.⁸ There is an alarming under-provision of consultant dermatologists in the UK. Compared with mainland Europe, the ratio of consultant dermatologists to the general population in the UK remains low: one consultant to every 130,000 people. This may well be in part due to a lack of exposure to dermatology at an undergraduate and postgraduate level, but it may well be due also to the lack of training posts available.⁸

Evidence indicates that nearly 13 million people will visit their GP with a skin condition each year which accounts for between 15 and 20 per cent of a GP's workload.⁸ However, it is recognised that GPs receive very little dermatology training (on average, no more than six days) compared with other medical specialties.¹⁰ A survey conducted for this report found that many CSU patients have to wait as long as 18 months before being referred.⁶

The referral pathway is often not clear to GPs or those living with CSU and once referred patients still face significant problems. Research from the Centre for Workforce Intelligence highlights that the number of specialist dermatologists is a concern. In July 2009 there were 91 vacant posts in the UK.¹⁷ These vacancies are spread around the country, but there are clusters of problem areas in the North West, Yorkshire and the Eastern regions.¹⁷

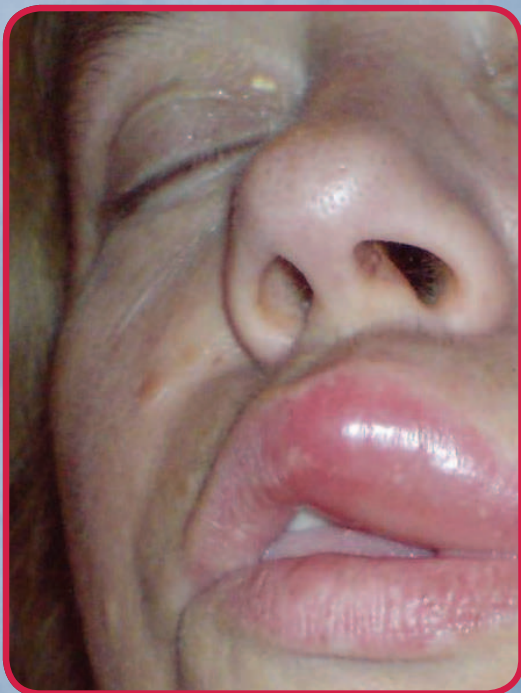
Some areas have seen a collapse of dermatology services, some survive on long term locum posts whose occupants are not trained to UK standards, and some provide a service limited to skin cancer and acute care. The geographical imbalances lead to variation in the level of provision of services around the UK.¹⁷ This places pressure on the specialists in these areas and prevents consultants from being able to effectively fulfil their governance obligations to other healthcare staff such as General Practitioners with specialist interest (GPwSI).¹⁷ Further to this, the Centre for Workforce Intelligence suggests that the lack of trainee dermatologists over recent years has seen “a significant failure of service provision for patients with significant skin disease, a collapse of some departments with no applicants for consultant posts, and a failure to provide support for the developing community based services.”¹⁷

There are primary care guidelines from the British Society for Allergy and Clinical Immunology (BSACI), further guidelines and referral criteria are available on the Primary Care Dermatology Society (PCDS) website.^{18, 19} However those contributing to this report believe the issue is the dissemination of these guidelines and lack of GP training in dermatology. Furthermore, the British Association of Dermatologists (BAD) note that there is a shortage of dermatologists for GPs to refer suitable patients to. Confusion around the patient pathway presents a particular challenge to patients and healthcare professionals alike.

Variation in access to specialist care and medicines across the UK

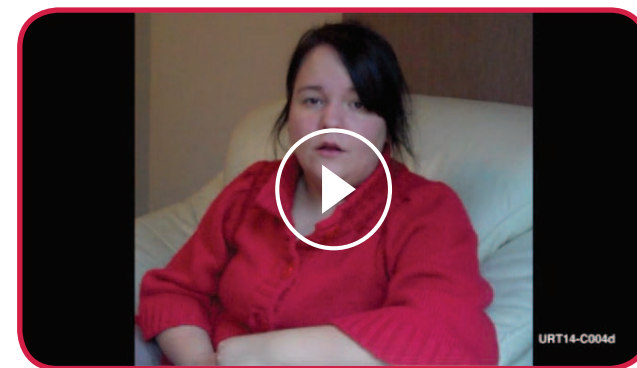
There is considerable variation in access to specialist care and medicines across the country. Whilst in some areas, people with CSU who need specialist treatment are referred to see a dermatologist or immunologist relatively quickly; there are many areas in the country where the wait is much longer. The All Party Parliamentary Group on Skin notes that hospital-based secondary care is an essential element in the management of skin conditions, however the shortage of dermatologists and the lack of priority afforded to the field means that service provision is unlikely to improve.⁸ Compared to other dermatology conditions, the availability of specialised urticaria clinics is patchy across the UK. For example, some patients with CSU may have to be referred to tertiary centres outside of their local area.





“ A significant proportion of the people I see living with CSU have previously been misdiagnosed due to confusion relating to the cause of their symptoms. The disparity we see across the country in terms of the management of the condition also explains why patients may face misdiagnosis or face a long wait to receive the correct diagnosis. One way to ensure early and correct diagnosis of CSU is for common care pathways to be developed which include primary care, dermatologists and immunologists in the identification and management of CSU. ”

Dr Sinisa Savic, Consultant Immunologist, St James's University Hospital, Leeds



The All Party Parliamentary Group on Skin recently reported on the large psychological and social impact that skin diseases can have on people's lives. However, only 3 out of 127 hospitals have a dedicated psychodermatology service, a reduction since 2004. This runs contrary to the Government's stated aim of established a parity of esteem between physical and mental health services. NHS England should seek to increase the number of psychodermatologists in England, and encourage CCGs and Acute trusts to establish dedicated psychodermatology services. Local Healthwatch organisations should ensure that patient's views are taken into account when services are being commissioned.

Within this report the group note the lack of a dedicated lead within NHS England for dermatology. In order to facilitate these improvements, it is important that CSU is recognised as a priority within national policy levers. Currently there are no CSU specific indicators within the Quality and Outcomes Framework (QOF) or planned Quality Standards to pinpoint best practice. Similarly, whilst dermatology is linked to NHS Outcomes Framework Domain 2 and 4 there are no specific indicators for either dermatology or CSU. The lack of national leadership compounds this problem. Unlike other conditions such as cancer and diabetes, there is no National Clinical Director for Dermatology.

A greater national policy focus on CSU would help to address many of the problems identified throughout this report. For instance, specific QOF indicators could incentivise increased dermatology training and enhanced psycho-dermatology support. Similarly, the development of CSU clinical guidance could precipitate the development of a quality standard, ensuring the condition has parity with other dermatological conditions such as psoriasis.

Quality standards are designed to drive measurable improvements within a particular disease area and CSU specific guidance would help to address the lack of consistent clear regional/local guidelines for the condition and better identify what best practice looks like.

More broadly, whilst dermatology is linked to NHS Outcomes Framework Domain 2 and 4 (enhancing quality of life for people with long-term conditions and ensuring people have a positive experience of care) there are no specific indicators for either dermatology or CSU. When NHS England considers the topics for inclusion within the 2015/16 framework, they should include specific indicators for dermatology. This could include reference within domain two for the effective provision of psychological support and clarity for HCPs on the treatment options available.

We know living with a dermatological condition can have a detrimental impact upon people's everyday lives. A review of a number of research papers examining the impact of various skin conditions shows that CSU has a particularly negative impact on quality of life, greater than acne, alopecia and even leprosy.²⁰ The detrimental impact CSU can have upon a person further demonstrates the need for enhanced support for CSU services at a policy level.

On average it can take between 6 and 18 months for a person living with CSU to receive a correct diagnosis.¹¹



“ There is a need for more education in general practice on the mechanisms and management of CSU, which would allow for earlier control of symptoms in many patients and appropriate referrals. ”

Dr Nuala Lynch,
GPwSI in allergy,
Frimley Park Hospital
NHS Foundation Trust

“ We need to ensure our colleagues in primary care are clear on how to increase antihistamine dosages for people living with CSU. We should also explore new treatments for those that still have symptoms on increased doses of antihistamines. ”

Dr Sinisa Savic,
Consultant Immunologist,
St James's University
Hospital, Leeds

A summary of the key challenges

From the discussion within this report thus far, six key challenges have been clearly identified and can be summarised as follows:

Lack of national guidance or prioritisation

- Currently there are no CSU specific indicators within the Quality and Outcomes Framework (QOF) or planned Quality Standards to pinpoint best practice
- There are no specific indicators for either dermatology or CSU
- There is no National Clinical Director for Dermatology

Lack of specialist knowledge of the condition in primary care

- In many cases, local commissioners do not regard CSU as a priority and therefore services in these areas are not invested in – a problem which is illustrated by the lack of a National Clinical Director for Dermatology which could help ensure national equity for CSU services
- In particular some clinical commissioning groups do not see the importance of training more GPs with a special interest (GPwSI) in dermatology, these GPs could greatly help expedite the diagnosis and treatment of those with CSU

Delay in referral and correct diagnosis

- The *Wheals of Despair* patient audit revealed that a worryingly high proportion of people diagnosed with CSU have to wait for as long as 18 months or more to get a referral to see a specialist⁶
- One of the main reasons for delay may be confusion regarding the need for diagnosis of CSU, especially when cause for urticaria (wheal formation) cannot be established
- In addition, many GPs are operating in a system where the numbers of referrals are limited

Confusion between CSU and allergy

- The majority of people living with CSU initially believe, or are wrongly informed, that their condition is caused by an allergy to a particular substance and inevitably become frustrated trying to seek out the allergen when there is none
- Educating patients on the lack of an allergen (and conversely the role of triggers, such as stress, which may cause an episode) is an important part of empowering people who live with CSU

Lack of psychological support for people living with CSU

- Despite the tremendous impact CSU can have upon those that live with the condition, there remains a lack of dedicated psychodermatological services to support those living with skin conditions
- The All Party Parliamentary Group on Skin note that the benefits of psychological interventions continue to be largely unrecognised⁸

Lack of access to efficacious treatments and clarity regarding treatment options

- Some GPs are reluctant to increase the dose of antihistamines and pharmacists may be resistant to dispensing higher doses of antihistamines
- Many clinicians rely on the use of medicines not designed or licensed to treat CSU. For example, corticosteroids which, although can be effective, are not appropriate for the treatment of CSU over long periods of time
- There's a critical need for rapid access to new treatment options as up to 40% of people with CSU derive no benefit even from increased antihistamine doses¹²

“ We can help patients understand their condition by dispelling the myth that CSU is caused by an allergen. It is important to make sure patients receive a swift and accurate diagnosis in primary care and referral to secondary care, which will empower them in managing their CSU and receiving optimal treatment. ”

Julie Van Onselen,
Independent Dermatology
Nurse Specialist, Oxford





A call to action

How can we overcome the challenges of CSU and improve the lives of those living with the condition?

There are a range of steps that can be taken to improve the diagnosis and management of CSU, ultimately helping people living with CSU regain control of their lives. The key steps which the *Wheals of Despair* taskforce believe should be urgently prioritised are detailed below.

Challenge	Solution	Who?
1) Lack of national guidance or prioritisation	<p>Prioritisation with Policy Levers</p> <ul style="list-style-type: none"> Whilst dermatology is linked to NHS Outcomes Framework Domain 2 and 4 there are no specific indicators for dermatology or CSU. This lack of focus must be addressed. Development of CSU specific NICE indicators within the Quality and Outcomes Framework (QOF) 2015/16 could focus on the recommendations made within this report relating to delays in referral and/or correct diagnosis. To ensure parity with other dermatological conditions, NICE should designate CSU as a topic requiring clinical guidance and subsequently a CSU specific quality standard, which would highlight best practice. Established links between CCGs and patient groups/community support services which GPs, nurses and pharmacists are aware of, could ensure patients are directed to the appropriate groups for additional support if required. 	<p>NICE, Department of Health, NHS England, Public Health England, CCGs and Health and Wellbeing Boards.</p> <ul style="list-style-type: none"> This is an ongoing priority and it is important that the next round of proposed indicators for QOF and NICE clinical guidelines have CSU specific proposals.

Challenge	Solution	Who?
2) Lack of specialist knowledge of the condition in primary care	Empower GPs and streamline referral pathway <ul style="list-style-type: none"> There is a critical need to educate GPs and other primary care clinicians on the appropriate management of CSU and when to refer. 	GPs, nurses, specialists and commissioners/policy makers <ul style="list-style-type: none"> All levels of the patient pathway should be included in the development of local/regional guidelines. Education is needed on the current British Society for Allergy & Clinical Immunology guidelines. Commissioners have a special role to play in providing and funding GPs with a special interest in dermatology. Commissioners can also work with the BAD, Royal College of GPs, PCDS to provide further training to GPs.
3) Delay in referral and/or correct diagnosis	<ul style="list-style-type: none"> Establishing more GPs with a special interest throughout the country will allow for best-practice sharing. Ensuring there are consistent clear regional/local guidelines outlining where GP-led management is appropriate and when specialist referral is required will help reassure and empower GPs on the management of CSU. As highlighted by the All Party Parliamentary Group on Skin, there is a need for a National Clinical Director for Dermatology to inspire a nationwide re-prioritisation of dermatology. 	
4) Sufferers' confusion between CSU and allergy	Patient education <ul style="list-style-type: none"> Those with CSU require education on the origin of CSU to dispel the myth that CSU is caused by an allergen. Ensuring people with CSU have accurate information about the causes and prognosis of their condition, provided by healthcare professionals and patient groups such as Allergy UK, is a key way of providing support. 	Patient support groups, GPs, nurses and specialists <ul style="list-style-type: none"> A range of individuals and organisations (such as Allergy UK) are well-placed to provide education and support to people with the condition.





Challenge	Solution	Who?
5) Lack of psychological support for people living with CSU	<p>Prioritise psychological interventions for people living with CSU</p> <p>In line with the All Party Parliamentary Group on Skin's recommendations for skin conditions more generally:</p> <ul style="list-style-type: none">• GPs and specialists need access to a range of supportive services, including psychological support, access to social workers and occupational therapy.• Healthcare professionals should be made aware of patient support groups who are able to provide information and counselling to their patients.	<p>Commissioners</p> <ul style="list-style-type: none">• Those commissioning care can arrange GPs and specialists to have access to supportive services. <p>The Medical Research Council</p> <ul style="list-style-type: none">• Can co-ordinate research to establish the clinical and cost-effectiveness of psychodermatology services. <p>GPs, nurses, specialists</p> <ul style="list-style-type: none">• Should highlight the role of supportive services, once available.

Challenge	Solution	Who?
6) Insufficient access to efficacious treatments and clarity regarding treatment options	<p>Provide clarity to HCPs on treatment options available</p> <ul style="list-style-type: none"> The European-level EAACI/GA2LEN/EDF/WAO guidelines recommend healthcare professionals increase antihistamines up to four times the licensed dose to relieve the symptoms of those with CSU, yet many GPs remain reluctant to do so.⁹ To ensure people with CSU receive the care they deserve updates to the UK-level guidelines (through the British Association of Dermatologists and the British Society for Allergy and Clinical Immunology) are required, reflecting changes to current best practice management of CSU. GPs need to be educated on the latest guidelines and of the option to increase the dosage of antihistamines in the appropriate patients; pharmacists will also need to be educated on the rationale to this increased dose in order to remove another potential barrier to patient access. There is an urgent need for appropriate and timely treatment escalation for those failing on first-line therapy to ensure more widespread access to the latest therapeutic strategies. 	<p>GPs, pharmacists and specialists</p> <ul style="list-style-type: none"> Specialists have an important role to play in providing education and reassurance to GPs and pharmacists on the implementation of the guidelines and to increase awareness regarding alternative treatment options available via secondary care if antihistamines do not work. <p>The pharmaceutical industry, GPs, nurses and specialists</p> <ul style="list-style-type: none"> Industry should invest in researching and developing new treatments for CSU. <p>Specialised services commissioning groups</p> <ul style="list-style-type: none"> Through the development of commissioning policy, the Specialised Dermatology clinical reference group (CRG) has the opportunity to make recommendations regarding funding and access to new treatment options for CSU in advance of review by NICE so that the latest treatments are made widely available on the NHS as quickly as possible.





Conclusion

People living with CSU find themselves trapped in a cycle of despair due to the condition's physical, emotional and psychological impact on their daily lives.

It often takes over 18 months for a correct diagnosis to be given, with those with CSU unable to lead normal lives in the meantime due to the misery of the condition. Once diagnosed, despite new treatment options recently becoming available for people with CSU who do not respond to standard antihistamine therapy, healthcare professionals and those with the condition are not necessarily aware of what treatments are appropriate and which ones are available to them.^{3,12} People living with CSU may benefit from psychological support to help them manage the considerable emotional burden of living with the condition, however this support is not widely available at present. Other challenges, including low levels of knowledge and education about the condition, prevent those with CSU from receiving the care that they desperately need.

We now have a chance to tackle the challenges people living with CSU face head on and radically improve their lives, allowing them to break free from their *wheel* of despair.

References

- 1 Weldon DR, Quality of life in patients with urticaria and angioedema: Assessing burden of disease. Allergy Asthma Proceedings: 27(2): 96-00
- 2 Sánchez-Borges M, Asero R, Asotegui IJ, et al. Diagnosis and treatment of angioedema: a worldwide perspective (position paper). World Allergy Organization Journal.2012; 5:125-147
- 3 Maurer M, Weller, K, Bindslev-Jensen C, et al. Unmet clinical needs in chronic spontaneous urticaria. A GA2LEN task force report. Allergy. 2011; 66: 317-330
- 4 Population Estimates for UK, England and Wales, Scotland and Northern Ireland, Mid-2011 and Mid-2012. Office of National Statistics. <http://www.ons.gov.uk/ons/rel/pop-estimate/population-estimates-for-uk--england-and-wales--scotland-and-northern-ireland/mid-2011-and-mid-2012/index.html> [Accessed June 2014]
- 5 Office for National Statistics. 2011 UK Census: Population density, local authorities in the United Kingdom. Table QS102UK.
- 6 Wheals of Despair market research amongst 103 patients. November 2013-January 2014
- 7 O'Donnell BF, Lawlor F, Simpson J, Morgan M, Greaves MW. The impact of chronic urticaria on the quality of life. British Journal of Dermatology 1997;136:197-201
- 8 The Psychological And Social Impact Of Skin Diseases On Peoples' Lives (2013). The All Party Parliamentary Group on Skin. <http://www.appgs.co.uk/publications/> [Accessed June 2014]
- 9 Zuberbier T, Asero R, Bindslev-Jensen C, et al. The EAACI/GA2LEN/EDF/WAO Guideline for the definition, classification, diagnosis, and management of urticaria: the 2013 revision and update. Allergy, 2014; DOI: 10.1111/all.12313
- 10 Response from Chris Bunker, President of the BAD, to Global Burden of Skin Disease in 2010: An Analysis of the Prevalence and Impact of Skin Conditions (2013). The British Association of Dermatologists. <http://www.bad.org.uk/News.aspx?sitesectionid=154&itemid=281&q=Response%20from%20Chris%20Bunker,%20President%20of%20the%20BAD,%20to%20Global%20Burden%20of%20Skin%20Disease%20in%202010:%20An%20Analysis%20of%20the%20Prevalence%20and%20Impact%20of%20Skin%20Conditions> [Accessed June 2014]
- 11 Wheals of Despair Advisory Board consensus. Meeting held December 10 2013
- 12 Maurer M, Rosén K, Hsieh, HJ, et al. Omalizumab for the Treatment of Chronic Idiopathic or Spontaneous Urticaria. New England Journal of Medicine. 2013;368:924-35
- 13 Reference TBC pending publication of 'Biologics in Dermatology' policy document.
- 14 Does Urticaria Rule Your Life? Patient leaflet available from Allergy UK (October 2013)
- 15 Maurer M, Bindslev-Jensen C, Gimwonz-Arnau A, et al. Chronic Idiopathic Urticaria (CIU) is no longer idiopathic: time for an update. British Journal of Dermatology. 2013 Feb;168(2):455-456
- 16 Mlynek A, Zalewska-Janowska A, Martus P, et al. How to assess disease activity in patients with chronic urticaria? Allergy. 2008;63:777-780
- 17 Dermatology: Medical Specialty Workforce Factsheet (2010). Centre for Workforce Intelligence.
- 18 Powell RJ, Du Toit GL, Siddique N, et al. BSACI guidelines for the management of chronic urticaria and angio-oedema. Clinical & Experimental Allergy. 2007; 37(5): 631-650
- 19 Urticaria: spontaneous urticaria (formerly chronic ordinary urticaria; chronic idiopathic urticaria). Primary Care Dermatological Society. <http://www.pcds.org.uk/clinical-guidance/urticaria-spontaneous-syn.-chronic-ordinary-urticaria> [Accessed June 2014]
- 20 Silveiras MR, Fortes MR, Miot HA. Quality of life in chronic urticaria: a survey at a public university outpatient clinic, Botucatu (Brazil). Revista da Associação Médica Brasileira 2011;57(5):577-82





WHEELS OF DESPAIR